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ABSTRACT

This document presents the text from two Senate hearings on the AIDS Federal Policy Act of 1987 which concerns voluntary testing for AIDS virus, education and counseling to stop the spread of AIDS (Acquired Immune Deficiency Syndrome), and confidentiality and discrimination against AIDS victims. In the first hearing, opening statements are included from Senators Edward Kennedy, Strom Thurmond, Orrin Hatch, and Dan Quayle. Testimony is provided by Louise and Clifford Ray, accompanied by their three hemophiliac sons, Robert, Richard, and Randy, all of whom have tested positive for the AIDS virus; their daughter Candy; their physician, Jerry Barbosa; and their attorney, William Earl. Also providing testimony are: (1) Alberta Fuentes and Katy Taylor, Commission on Human Rights, New York City; (2) Lonnie Bristow, American Medical Association, Chicago, Illinois; (3) Mary Foley, American Nurses Association, Washington, D.C.; (4) Bonnie Strickland, American Psychological Association; (5) Kristine Gebbie, AIDS Committee, Association of State and Territorial Health Officers, McLean, Virginia; and (6) Joan Banach, American Medical Record Association. Prepared statements are included from the American Hospital Association, the Coalition for AIDS Prevention and Education, and the National Hemophilia Foundation. Witnesses providing testimony at the second hearing include AIDS patient Michael Sisco; Mary Jane Edwards, founder of Mothers of AIDS Patients; Vernon Mark, associate professor of surgery, Harvard University; Anthony Robertson, Research Testing and Development Corp.; Robert McAfee, American Medical Association; and Gloria Rodriguez, AIDS outreach coordinator, Newark, New Jersey Department of Health. Prepared statements are included from Senators Edward Kennedy and Tom Harkin; James AuBuchon, American Red Cross Medical Operations; and the American Medical Association. Two reports of the AIDS Discrimination Unit of the New York Commission on Human Rights are also included. (NB)

S. Hrg. 100-515

# AIDS FEDERAL POLICY ACT OF 1987

ED325721

## HEARINGS

BEFORE THE

## COMMITTEE ON
## LABOR AND HUMAN RESOURCES
## UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

FIRST SESSION

ON

## S. 1575

TO AMEND THE PUBLIC HEALTH SERVICE ACT TO ESTABLISH A GRANT PROGRAM TO PROVIDE FOR COUNSELING AND TESTING SERVICES RELATING TO ACQUIRED IMMUNE DEFICIENCY SYNDROME AND TO ESTABLISH CERTAIN PROHIBITIONS FOR THE PURPOSE OF PROTECTING INDIVIDUALS WITH ACQUIRED IMMUNE DEFICIENCY SYNDROME OR RELATED CONDITIONS

SEPTEMBER 11 and NOVEMBER 18, 1987

CG 021017

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# AIDS FEDERAL POLICY ACT OF 1987

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FRIDAY, SEPTEMBER 11, 1987

U.S. SENATE,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
*Washington, DC.*

The Committee met, pursuant to notice, at 9:38 a.m., in room SD-430, Dirksen Senate Office Building, Senator Edward M. Kennedy (chairman) presiding.

## OPENING STATEMENT OF SENATOR KENNEDY

The CHAIRMAN. We will come to order.

I would like to welcome everyone to the Committee's third hearing on AIDS this year. Today we will focus on the AIDS Federal Policy Act of 1987 which addresses the issues of voluntary testing for AIDS virus, and the vital task of education and counseling to stop the spread of the virus. This bill will address the difficult problems of confidentiality and discrimination against those who are infected.

Although the AIDS epidemic has been with us over five years, the virus that causes it is still obscure. The full extent and the location of the virus is hidden because many of the people who carry it feel well and are unaware that they harbor it. Many others are terrified of the consequences of finding out that they do.

In contrast to this hidden danger are the human tragedies caused by this virus. They are visible and continue to multiply. They are now felt in every State and major city around the country, and they are increasingly present in smaller cities and towns.

How can we confront a disease that is so visible and so hidden at the same time? The key to this puzzle has been given to us by virtually every health organization in the country. We will never defeat this disease unless we protect those who harbor this virus from the painful and irrational consequences of that information. The twin principles that we must follow are confidentiality and anti-discrimination.

The medical, public health and scientific communities are united in their recommendation that education is our best hope to meet the challenge of AIDS. Everyone capable of passing this virus on or receiving it must learn how to stop its spread. This will never happen unless we speak freely to those who harbor the virus.

We must bring this devastating illness into the open. We will not succeed unless infected individuals believe that it is in their own interest to come forward and obtain the guidance and assistance of health professionals.

Today, we will have the moving story of one American family from Florida which has faced discrimination in many painful forms because three of its children were born with hemophilia and became infected with AIDS through transfusions. This family tragedy confirms everything we know about the need to fight the hysteria and fear with education. It demonstrates the destructive forces that can be readily unleashed when people react to fear with hatred and discrimination. It shows the importance of adhering to accepted standards of confidentiality and for providing individuals with protections against bias in all of its forms.

We will also hear today from the Human Rights Commission of New York City about the special problems facing minorities infected with the AIDS virus.

The legislation we have introduced reflects the recommendation of the Centers for Disease Control, the Surgeon General, the American Medical Association, and a broad range of other health organizations. There is virtually unanimous support from the professional public health community in the United States. A number of these health organizations are also here to testify today.

Senator Weicker.

Senator **Weicker**. I have no opening statement.

The **Chairman**. We will insert Senator Thurmond's opening statement in the record at the point.

### OPENING STATEMENT OF SENATOR THURMOND

Senator **Thurmond**. Mr. Chairman, I am pleased to attend this hearing on your legislation which would increase AIDS testing and counseling for high risks groups, protect the confidentality of testing and counseling records, and prohibit discrimination against AIDS victims.

AIDS has afflicted more than 36,000 Americans. By 1991, it is expected that 270,000 individuals will be diagnosed as having AIDS. Add to those cases the 1.5 million Americans who are estimated to have been exposed to the AIDS virus, and the dimensions of the public health crisis faced by this Nation take on overwhelming proportions.

While we do not yet know how to arrest the virus itself, or cure its victims, we are aware of the most common forms of transmission. We should use this knowledge to avoid contracting the disease by behaving in responsible ways. We should avoid spreading panic and unnecessary anxiety through misinformation and prejudice.

Recognizing the seriousness of this problem, I was pleased to be an original cosponsor of S. 1220, the Omnibus Acquired Immune Deficiency Syndrome Act of 1987. That legislation has been unanimously reported out of this Committee and now awaits action by the full Senate.

However, I have serious concerns about certain aspects of the legislation under consideration today. This bill would establish a federal right of action with significant penalties against those who are seeking to protect themselves from contracting AIDS. I question the wisdom of creating a federal right for persons, simply because they have a fatal and communicable disease.

I understand some of the witnesses here today support such an approach. Accordingly, I look forward to hearing their views on these and other matters concerning this problem.

Thank you, Mr. Chairman.

**The Chairman.** The prepared statements of Senators Hatch and Quayle will be inserted in the record at this point.

[The prepared statements of Senator Hatch and Quayle follow:]

From the office of

SEN. ORRIN HATCH

Washington, D.C. 20510

AIDS Federal Policy Act of 1987
September 11, 1987

Today, this nation faces not one but two epidemics. We are facing an epidemic of AIDS and an epidemic of fear. The treatment for both is the same, research and education.

The more we know about AIDS, the more we can reduce the spread of the virus and the fear associated with the disease. I am pleased that Senator Kennedy has called this important hearing today to examine the role that testing and counseling should play in educating the public.

It has been estimated that 1.5 million Americans have been exposed to the AIDS virus. Unfortunately, this is just an estimate. No one knows with certainty whether there have been 500,000 or 5 million Americans exposed. Because of this, one of our priorities should be a cross sectional study of Americans to determine what is the actual prevalence of infection with this virus. Knowing what the actual number is will assist us in making policy decisions in countless ways.

Whatever the actual number is, most of those Americans who have been infected probably don't know it. That is why it is critical that we increase the availability of AIDS testing.

Part of every testing procedure should be counseling. Counseling provides the opportunity to educate those who are not infected on how to keep from becoming infected. And just as important, testing centers have the ability to educate those who have been infected about what to expect and what support, services, and treatments are available.

Every American needs to know that by avoiding IV drug abuse and engaging in sex only in a faithful monogamous marital relationship, he or she has very little risk of becoming infected with AIDS.

Every American also needs to know that using IV drugs or having multiple sexual partners, with or without using comdoms, puts him or her at risk. Testing and counseling programs play an important part in this education.

Testing and counseling will not be effective without protecting the confidentiality of the results. But every state has laws which govern the confidentiality of medical records. Instead of the federal government's taking yet another responsibility away from the states, we should be encouraging the states to review their laws to make sure that they are still appropriate in light of the AIDS epidemic.

Senator Kennedy has introduced legislation which, in addition to addressing testing and counseling, also contains a new anti-discrimination statute. I have reservations about this provision because it may provide AIDS patients with greater protection than we have ever afforded other handicapped individuals. I hope during our consideration of this legislation that we will address this issue and make sure that we understand its full implications on the existing framework or rights and procedures.

I look forward to reviewing the testimony and responses to questions from this hearing. I hope that, by working with the members of this Committee, we can fashion responsible and effective testing and counseling legislation to help combat the AIDS epidemic.

# OPENING STATEMENT OF U.S. SENATOR DAN QUAYLE (R-IN) AT THE SENATE LABOR AND HUMAN RESOURCES COMMITTEE HEARING ON THE "AIDS FEDERAL POLICY ACT OF 1987"

September 11, 1987

Mr. Chairman, I am pleased that you have scheduled this hearing on the subject of developing a Federal policy concerning AIDS testing, confidentiality and discrimination.

AIDS is a catastrophic disease and a public health problem that poses significant challenges to American society and difficult policy choices for legislators. It is certainly one of the most complex ethical, legal and health problems that this country has ever had to face. It is not a problem that lends itself to either simplistic or to partisan solutions.

Health officials have repeatedly pointed out the need for more widespread testing and counseling in order to prevent the further spread of this horrible disease. This need is also usually discussed with the need for appropriate safeguards to protect the confidentiality of individual test results while also providing the necessary authority to disclose the information when public health needs arise. I agree completely with Senator Kennedy that we must address these issues in any Federal legislation authorizing funds for additional testing; but I completely disagree with the methods he has taken in his legislation to meet these needs.

Senator Kennedy's bill establishes Federal law with Federal enforcement to protect confidentiality and also defines in that Federal law the conditions under which disclosure can be made. I reject that approach. Confidentiality of medical records has traditionally been a matter of State law, enforced by State officials as well as by professional societies and professional ethics. I believe it is neither appropriate nor effective to supersede State law and substitute a new Federal enforcement agency.

My approach to dealing with these vital issues of confidentiality and disclosure is different. I am currently developing legislation that would authorize the necessary funding for AIDS testing and counseling. The approach I am taking would provide a block grant to the states and would require the States, as a condition of qualifying for grant funds to establish and enforce appropriate confidentiality and disclosure requirements.

My first difference with the Chairman's approach is that I would build on existing State laws and enforcement procedures instead of creating a new body of Federal law and a new Federal enforcement agency. The second major difference is that the substantive standards for confidentiality and disclosure would not be a new Federal pronouncement but would be based on those outlined in the Uniform Health Care Information Act that was drafted by the National Conference of Commissioners on Uniform State Laws. This Act was developed within the context of AIDS and its development was participated in by many of the organizations with the most expertise in the confidentiality of medical records, several which are represented at this hearing --- the American Medical Association, the American Medical Record Association, the American Society of Law and Medicine, the American Hospital Association, the American Bar Association, and the American Psychiatric Association.

The bill I am considering would require that states accepting Federal AIDS testing and counseling funds to, as a minimum, agree to abide by the standards for confidentiality and disclosure set forth in this model state law. This approach would require absolute confidentiality of AIDS testing and counseling records unless certain medical circumstances require it.

I have taken this approach for several reasons:

First, philosophically, I have difficulty with the supercession of state laws by Federal law .

Second, given the constantly evolving state of knowledge about AIDS, I believe that it is very important that we establish a flexible framework for making AIDS confidentiality and disclosure decisions. Thus, the approach I am considering would require that Federal AIDS testing and counseling funds be utilized under standards established by the Secretary based on the principles set forth in the Uniform Health Care Information Act. This approach would allow the circumstances under which disclosure would be permitted to be changed in accord with our evolving knowledge about AIDS without petitioning the Congress for statutory change.

Third, the special circumstances of AIDS and the often inhumane consequences that have followed inappropriate disclosures demand that confidentiality protection be strictly and effectively enforced. As a practical matter, I do not think that the Federal government can enforce these provisions. Therefore, the approach I am working on would require that the States enforce the confidentiality requirements; those states that did not adequately enforce these requirements would be faced with the loss of these funds.

In addition, the approach I am developing also focuses on the need to educate all the individuals who handle AIDS medical records about their obligations to maintain the confidentiality of these records. Again, my proposal would make this requirement a condition of receipt of Federal funds.

There is one other major area of difference between my approach and that of the Chairman. His bill makes it a Federal offense to discriminate against any person in employment, housing or public accommodations who is, or is regarded as being, infected by AIDS. My bill will not create such a Federal offense. Federal law does not now prohibit such discrimination on the basis of any other illness or handicap. There is, of course, a prohibition against discrimination against the handicapped in Federal-assistance and contract programs and that prohibition does apply to persons suffering from AIDS as a result of a recent Supreme Court decision.

I believe that we need a sound factual basis for the new leap in discrimination law that S. 1575 would create. The mere collection of egregious incidents, although certainly horrible and offensive, is not a sufficient basis for establishing such sweeping Federal policy.

Mr. Chairman, it is my understanding that additional hearings will be held to discuss many of the issues raised by AIDS testing and counseling in more detail. I consider it particularly essential that we explore the ramifications of the proposed anti-discrimination provisions so that we can have a full understanding of their implications before we act on them. I think these hearings will be very important in educating the Congress about these very important issues and I certainly commend you for scheduling them.

* * *

The **CHAIRMAN**. Our first witnesses this morning are Mr. and Mrs. Ray. Many of us have read about the Ray family from Florida and their difficulties over the past several weeks. Even though their experiences have been the subject of some public attention, I thought it extremely important that the Committee receive a first-hand account of what they have been through. We all can see the enormity of types of discrimination which is arising.

I want to welcome the Ray family today. I understand your doctor and lawyer are here as well. I suggest that you, Mrs. Ray and Mr. Ray, introduce everyone else at the table, and then we will proceed.

First of all, let me say that I think we are all mindful of how difficult it is for families to talk about health challenges, health difficulties, and health needs in their family. I think all the testimony that we hear, whether it is in this Committee, in the Education Committee, the Armed Services Committee, or Environmental Affairs Committee is important for the legislation; but in many instances, it is the most difficult to give. We understand that, and we appreciate your willingness to share your experience with us here this morning.

We get our information from many different sources. Today, we are going to get extremely important information from some very young sources. They are the children that we see sitting on the front row back there. We want to extend a very warm welcome to them. We had the opportunity to meet them in the anteroom just before, and we want to say what a delight it was to have a chance to greet all of them.

We know that if they feel from time to time they would like to duck out of the hearing for a drink of water or something like that, that is okay, too. They are very welcome here.

Mrs. Ray, we will be glad to hear from you. Perhaps you would like to introduce both your doctor and your attorney, and then you might introduce each of your children and ask them to stand up. We would like to meet them.

## STATEMENTS OF CLIFFORD RAY, LOUISE RAY, ROBERT RAY, RANDY RAY, RICHARD RAY, AND CANDY RAY OF ARCADIA, FL, ACCOMPANIED BY DR. JERRY BARBOSA AND WILLIAM EARL, ATTORNEY

Ms. **RAY**. I would like to introduce my children first then.

The **CHAIRMAN**. Fine. That's a good priority.

Ms. **RAY**. Richard Ray, age 10; Robert Ray, age 9; Randy, age 8; and Candy, age 6.

Senator Kennedy and members of the Committee, my name is Louise Ray. My husband Cliff is to my left, and also to my left is our physician, Dr. Jerry Barbosa. Also seated at the table to my right is William Earl, our lawyer.

As you can see, our boys, Ricky, Robert and Randy, are active and healthy boys. Merely because our boys had a blood test which showed them to be positive for the AIDS virus antibodies, our family has been threatened, harassed, and discriminated against. My daughter, Candy, and Cliff and I have all tested negative.

Our boys are moderate hemophiliacs who sometimes require injections of clotting agents. Dr. Barbosa believes that Ricky, Randy and Robert's positive test results have resulted from the boys' taking clotting agents for their hemophilia.

After learning of our boys' positive tests and discussing with Dr. Barbosa the implications of the test, I went to my pastor at my church in Arcadia, Florida, seeking counseling. The pastor said it would be a good idea if we no longer came to the church.

We then went to the children's schools to tell them of the boys' HIV positive status. The school officials said our boys should stay home just temporarily. This temporary absence has turned out to be more than a year. This was only done because the boys' blood tests were positive. Our boys have no disability and none of the symptoms of ARC or of AIDS. The school officials would not listen to Dr. Barbosa or the other doctors. The only place that we had left to go for help was in Federal court. Mr. Earl filed a lawsuit in June, and the judge decided that the boys' exclusion from school was illegal. She ordered the Desoto County school system to allow the boys back into a regular classroom.

Under this injunction, we took the boys back to their regular classes in August, and they were only in classes a week. During this week, a group in Arcadia organized a boycott against the school, there were two bomb threats, and we received threatening calls.

During their one week in school, the boys were kind of unsure if they wanted to continue going to school. My husband, Cliff, told them to go ahead and finish the first week and then they could make a decision if they wanted to stay. At the end of the first week on Friday afternoon, the boys decided they wanted to continue to go to school. They had begun to make friends and were beginning to feel accepted again. Cliff and I were really happy about this because they deserved a normal life and normal friends. That same night while we were away from home, our home in Arcadia was burned. The state fire marshall is still investigating the fire, and we have lost everything that we had in the fire.

After our house burned, we stayed in a motel at an undisclosed located. We were asked to leave the motel because of the boys' status. Also, the person who has normally cut our boys' hair for several years refused to cut their hair when she learned of the positive HIV status.

We have decided not to go back to Arcadia, and we are looking for another community in Florida where our boys can return to some kind of a normal existence. We have received thousands of letters, calls and donations from all over the country, and we want to thank everyone who has helped us during this time.

If anything good can come out of what our family has gone through, we are hoping that it is families whose children test positive can get help against the kind of discrimination that we have met against. I know that there has got to be other families out there that are suffering the same thing and are trying to hide it because they are afraid. We just hope that you will help families like ours and stop discrimination against people whose only problem is that they have tested positive for HIV.

I would like to thank you very much.

The **Chairman**. Thank you very much.

Before I get into some of the specifics, let me just ask your children if they would tell us what grade they would be in if they were going to school. Let us start off with Ricky. Stand right up. What grade would you be in if you were going to school?

Master **Ricky Ray**. Fifth.

The **Chairman**. Let me ask Randy. What about you?

Master **Randy Ray**. Second.

The **Chairman**. And Robert?

Master **Robert Ray**. Fourth.

The **Chairman**. And Candy?

Miss **Ray**. Second.

Ms. **Ray**. No. First. [Laughter.]

The **Chairman**. Always trying to get ahead, promoting yourself, I know.

Are they at the present time attending any schools?

Ms. **Ray**. Not at present. We are looking for a school system. Judy Kavanaugh is meeting with school officials today and trying to make arrangements to get them back into school for us.

The **Chairman**. Ms. Ray, I notice that there is no mention in your statement of where you are living now. Was that intentional?

Ms. **Ray**. Yes, it was. We have not disclosed where we are living at the present because we would like to keep it quiet until we can get the boys into school, hopefully without a lot of media attention, and kind of ease them in quietly. We just want to get back to a normal life and a normal routine.

The **Chairman**. How much real danger do you think you are in? Is it your conclusion that if people know about this in the community or the school district that you would be in some kind of danger, or would experience discrimination?

Ms. **Ray**. In the district we are in now?

The **Chairman**. Yes.

Ms. **Ray**. Where we are at now, we have been passing people in the stores or whatever. People have been very supportive. But we would just like to get the kids into school quietly. It is disrupting to a life when you are thrown into something like this. We just want to get back to normal and get the kids in and try to get them back on to a routine of some kind.

I really do not feel at present where we are that we would be in any danger.

The **Chairman**. Before getting into the incidents of discrimination, maybe we could go back a little bit to Arcadia. Do you have any idea how the people in Arcadia first became acquainted with the health problems of your children?

Ms. **Ray**. Well, to be honest, what had happened there is I went to my minister for counseling. A couple weeks later, he came back to my home and asked me if we needed any help financially, because one of the boys was in the hospital and had some minor surgery, and the hospital he was in is approximately a hundred miles away. And I told him, yes, that we could because the gas that we were using back and forth was getting hard.

So he told me that he would need to speak with some of the men of the church and that he would get back with me. They came back later that afternoon. He brought the previous minister with him who was still attending the church, and they told us they were receiving calls from parents who were threatening to sue the church, were threatening to pull their kids out of the church there because my boys were in church with them. He said he thought it would be better if we did not come back.

At this point, I really did not ask him how the people found out. Looking back, I really should have.

When they left that afternoon we went to tell the school, because we were afraid that if the parents were calling the church, they were going to call the school next. I mean, you are only in church for a few hours a week, and in school you are in there seven hours a day.

So we kept the boys out for approximately a week to see what was going to happen. The school never received not one call. Looking back now, I think what happened is these two ministers were afraid, and this is something that they came up with to pacify themselves. I really do not think they received any calls. But by me going to the school board, it opened it up.

The CHAIRMAN. Mr. Ray, would you like to make any comment about how you think the people of Arcadia first became aware of the test results.

Mr. RAY. It was when we went to school board, I believe, because it started leaking out little by little from there. We were told by the school board that it would be kept confidential through this, but one of the newspapers in town, his wife works for the school board, and he knew about it at that time because she went home and told him. People working within the school facility were telling different people that around. In a community as small as what that is, it is easy to get out.

The CHAIRMAN. How big is Arcadia, Ms. Ray?

Ms. RAY. Arcadia is about 6,500. The county, I think, is 20,000, I believe. I am not positive, but Arcadia is about 6,500.

The CHAIRMAN. It is really amazing to have to ask questions like this. I think there is a sense in most communities around the country that people like to help each other, find out what is happening in different families, find out the needs of their neighbors, and reach out to try and help. People generally want to assist their neighbors, their friends, their family and their community or members. You really have to ask yourself what kind of society we are. I think it is probably particularly difficult for children to hear when you have to ask what kind of society we are when we have that kind of a reaction which you have just related to us.

I just have a few more questions and then I will yield to my colleagues. Could you tell us just a little bit about the incident with your family barber? I understand the children went for a haircut. Tell us about the barber. Did she tell any of you exactly what she was afraid of?

Mr. RAY. Well, I went there. When I pulled up, I told the boys to sit in the car, and I went to her and I asked her——

The CHAIRMAN. They needed their haircut, right?

Mr. RAY. I went to her and I asked her, I said, "Will you cut our hair?" Because at this time it was out about the kids being positive. She said, "No." I said, "Why?" She said, "Well, you know why. It is in all the papers."

I said, "Well, thank you anyhow," and I left.

The Chairman. Did she tell you what she was concerned about?

Mr. Ray. No. She just said she could not do it.

The Chairman. Did you ever have a chance to talk to the pastor about what he was concerned about? Was it that you were going to be sitting in the church pews? Did he say that people were concerned about having to sit next to you or something like that?

Mr. Ray. Their concern when they came to the house was the other people's reaction, like being sued and they were threatened.

The Chairman. The church being sued?

Mr. Ray. Yes. It was their concern, what we got from it, you know Mr. Gamiotea stated that he was scared to death but he would deal with it somehow. He was the previous minister before that.

The Chairman. It is difficult as a lawyer to understand on grounds the church was concerned about being sued. I mean, if you read back in the Bible, the teachings of the Judeo-Christian ethic all involve reaching out to the sick and the lame and the homeless.

OK, what about the hotel people? Tell us about your run-in at the hotel.

Ms. Ray. Well, after the fire, we went——

The Chairman. What fire is that?

Ms. Ray. After my house burned.

The Chairman. This was shortly after the community became aware?

Ms. Ray. This was on Friday afternoon at the end of the first week of school. After the judge had ruled that the boys could go back, they went to school for five days. The evening of that day, which was Friday, there was a group that was formed in Arcadia called Citizens Against AIDS in School. This group wants mandatory testing of all school students and all teachers and then segregation of those that come positive.

They were holding a press conference on that evening, and every evening that this group has met or has had, I should say, the media there, we have left. We have not stayed in town. So we left that evening, and our house burned.

Well, the following day, we went to a motel out of Desoto County. The gentleman there knew who we were; he rented the room to us; he was very sympathetic. We rented the motel room for three days. The third day I had been out, and I came home to the motel and there was a note on the door that said, "Please call office immediately." So I picked up the phone and I called, and a lady answered who apparently, in talking to her, she was the manager's wife. I said that we were going to renew it for another three days, and she said, "Well, we have a problem."

I asked her, I said, "Well, what is it? Maybe we can work it out." She said, "Well, the owners now know who you are, and they do not want you here. The maids refuse to come in and clean your rooms because they are afraid." She said, "My husband has been bringing your towels in and taking the trash out. The maids will not go anywhere near the room, and we want you to leave."

So rather than argue—because there was no sense in arguing with the people, if they do not want you there, you do not want to stay—we left.

The CHAIRMAN. When your house burned down, this was the end of the first week.

Ms. RAY. Right.

The CHAIRMAN. Did they ever find out who had burned it down?

Ms. RAY. The fire marshall's investigation was complete, and the sheriff has it but it has not been released.

The CHAIRMAN. Mr. Earl, you are the Ray's lawyer. How do you see the situation? Is the problem just knee-jerk prejudice or is it a lack of knowledge or both? Or is there something else involved here?

Mr. EARL. Unfortunately, Senator, this family has gone through a tragedy beyond what most families could be expected to endure, but they represent a generic situation. My wife and I, who is also a lawyer and co-counsel working with the Rays, now have two other cases just in the small area of Florida of people coming to us, families coming to us with the identical situation.

My perception of the overall situation is there are many, many more families that have been driven underground by this ignorance, hysteria, and I think particularly in this case, in this community—you are always going to have a minimum level of ignorance and hysteria and fear by people who do not want to learn the facts. But in this town of Arcadia, Florida, added on to that you have the elected school officials and other elected officials, local governmental officials who are actually exploiting that situation, who are telling this ignorant, blindly prejudiced element that it is okay; not only that it is okay, but we may well pat you on the back for what you are doing here in getting these people out of town. So you have a total absence of leadership.

I would go beyond that, and I would say the local governmental officials there are exploiting this situation politically. Coupled with that, in our State of Florida, we have had no leadership to date—I hope something will be forthcoming—at the state level.

These people have no place to turn. They called me on the motel situation. That is public accommodations on a Federal highway down in Florida, a substantial motel. There is no protection. The only reason they were asked to leave that hotel is because those little boys had a positive blood test. They are healthy, active, vigorous little boys. They are not sick. They do not have AIDS; they do not have ARC.

That is the problem. There is an absence of local--the local government in this particular case is exploiting the situation, and there has been no action at the state level.

The CHAIRMAN. Let me ask you, Dr. Barbosa, in addition to your role with respect to the Ray situation, you are chief of pediatric hematology at All Children's Hospital in St. Petersburg?

Dr. BARBOSA. That is correct.

The CHAIRMAN. Have you seen situations similar to the Ray case?

Dr BARBOSA. Yes. There are the two cases that Mr. Earl mentioned who are my patients also. I must say that when the Ray family informed me of what was happening in Arcadia with the school board, my first reaction, of course, was to get in touch with the school superintendent, Dr. Browning. I offered him all available information on aids such as the CDC guidelines, the Surgeon

General's report, AMA recommendations, et cetera. I also offered to come to Arcadia myself to give seminars or conduct workshops for everyone in the school system. And what was his answer? "No, thank you. We do not need you."

The **CHAIRMAN**. As I understand it, you were the doctor who actually recommended that the Ray children be tested; is that right?

Dr. **BARBOSA**. Well, I saw the Ray family for the first time in August 1986 when they were referred to all Children's hospital for minor surgery. Before that, they were being cared for by a local physician in Arcadia. I was contacted by the physician that was to perform minor surgery on one of the children. He requested that I become involved in the case due to the hemophilia situation to be sure that the bleeding problem would be under control during surgery.

It was then that I met with the Ray family, and we discussed the options that they had such as, whether or not to go ahead with the testing for the HIV antibody. Mr. and Mrs. Ray agreed and decided to go ahead with the testing. As expected, it turned out to be positive.

When the first boy was found to be positive, they requested that the whole family be tested. The other two children who also suffer from hemophilia were positive. Mr. and Mrs. Ray and Candy Ray, their daughter, are negative.

The **CHAIRMAN**. Based on what you know now, in terms of what has happened to this family and others, would you make the same recommendation the next time?

Dr. **BARBOSA**. No, sir.

The **CHAIRMAN**. Why not?

Dr. **BARBOSA**. I would not because of the blatant discrimination encompassing this country, and the entire the world, concerning patients infected with the HIV. The rules and regulations or guidelines for anyone performing any type of surgery or for anyone dealing with children in a school situation exposed to body fluids or secretions, should he the same whether or not they have children that are positive or negative.

There are infections such as hepatitis, which are far more contagrious than AIDS for which they should be following the same recommendations. They do not have to do anything different for children who are HIV positive as far as preventing the spread of the disease.

Moreover, the CDC, out of concern for the families of children with hemophilia, has conducted extensive studies in household contacts; by that I mean families sharing toothbrushes, razors, etc, and yet there is not a single case in the whole country that other than by sexual contact have turned out to be positive for the HIV.

If I felt in any way different than what I have stated, I would not have had these children for part of the weekend when their house was burned in my own home swimming and playing with my own children.

The **CHAIRMAN**. But if no one gets tested or if the testing is no longer done by the traditional health institutions and settings, will we not be just driving the whole problem underground?

Dr. **BARBOSA**. We need regulations, Senator Kennedy. We need something that really guarantees confidentiality.

The **Chairman**. Well, I will just close with the observation that it is precisely this kind of situation that we are hoping to avoid. By passing some tough legislation to deal with this problem and deal with both the confidentiality and the discrimination question. I want to indicate to you Dr. Barbosa, that you have made the case for legislation as well as it could ever be made. I know it has been a difficult situation, but I am grateful to you for coming to discuss this with us today.

Senator **Weicker**. Thank you very much, Mr. Chairman. I have just got two questions, one of Dr. Barbosa and one of Counselor Earl.

Dr. Barbosa, what threat do these boys pose to their schoolmates?

Dr. **Barbosa**. None whatsoever, Mr. Weicker. There is not one case in this country where AIDS has been contracted in the school system by casual contact.

Senator **Weicker**. Well, I thank you for the response because I think that point ought to be made again and again and again, because what is going on here is not unique to the Rays. It is going on in my state and every other state of the union. Rather than take these most precious of our resources to our hearts, we are driving them out for the reason that people think their children are threatened.

Dr. **Barbosa**. That is correct.

Senator **Weicker**. So I am glad to have your response that they pose no threat to their schoolmates.

Counselor, my question to you is on the political leadership in this matter. I am not here to go ahead and cast any stones because, believe me, we are lacking a little bit of that here at the Federal level also. But I would like to ask you as to exactly what the responses have been to the Rays' situation right from the top on down, from the Governor's office. Has there been assistance from the Governor's office?

Mr. **Earl**. We, the Rays and I, have yet to hear from the Governor's office.

Senator **Weicker**. The state school board, superintendent of schools of the State of Florida?

Mr. **Earl**. We have contacted and asked the State Education Commissioner, Betty Castor, to take some action, not only because of the Rays but because of other similar situations. One of the problems, Senator, is that each county in Florida has an independent elected school board. We have a school board like Arcadia which is, I would say, neanderthal in terms of what we have seen in this case. On the other hand, we have other school boards such as Dade County, Florida, and Sarasota County, which after this tragedy adopted a very forward-looking, courageous policy of following the CDC guidelines, providing confidentiality. But one of the concerns of the members of that school board was: I am in favor of this policy, this school board member said, but are we going to become a dumping ground for the rest of the state because we have no state leadership and to date no national help on this. And I think that was a very valid concern, that communities' elected officials at the local level who are showing some courage and doing the right thing are rightfully worried that they are going to become magnets for children with this condition from all over the state. So I think we need some state and national help on this.

The short answer is we have had nothing from the state government to date, and obviously there has been nothing from the Federal Government to date, other than I would say what has been a mainstay—and I know Dr. Barbosa has found it so—Surgeon General Koop, the CDC had been a pillar of strength for this doctor who has many other cases like this.

Senator **Weicker**. Dr. Barbosa.

Dr. **Barbosa**. That was one of my biggest frustrations, Senator Weicker, when I was confronted with this situation. By the way, I have another case that came before the Ray family case; they are still going to court.

I called the Surgeon General's office. I must say that they were most helpful in every way. I called the American Academy of Pediatrics who sided with us. I called the CDC; they were extremely supportive. The AMA requested to get involved in the case even without us asking them to do so.

I called the Commissioner of Education of the State of Florida. She was the only official, the only person that declined to return my call. After a few days, a Mr. MacKenzie, who identified himself as being a legal counsel for the Commissioner of Education in the State of Florida, said, "What can we do for you?" I said, "Sir, I am calling your office because I need help, I need guidance. You must be familiar with the Ray family situation. He replied, "Sure, we all know about that."

I said, "You must agree with me that it is blatant discrimination, what is happening to these children." And what was the answer? He said, "Blatant discrimination? Well, that is your very personal opinion." And that was the answer I was given.

Senator **Weicker**. In your testimony you indicated you offered to go down to the school district and educate.

Dr. **Barbosa**. Absolutely. Yes.

Senator **Weicker**. Do you think it absolutely essential that the education process take place across this country in every school district of the country?

Dr. **Barbosa**. Not only among the lay people; also among the medical communities.

Senator **Weicker**. Well, just so that it is not felt from these hearings that we are coming down on the head of the State of Florida, we are sitting here in the United States Senate now with a bill that was passed out of this Committee calling for explicit education the width and breadth of this nation and other measures to be taken so far as AIDS is concerned. We are sitting here in the United States Senate where we have had nothing but an occasional cloture vote now for two, three, and four weeks, and we cannot get that bill on the floor to get it voted on. So the discrimination, the prejudice and everything that goes on, believe me, comes all the way up to the Federal level.

Here there are these situations occurring. The loss of a home, I am sure the Rays would say, is bad, but what is happening to their kids is worse. And we have to fiddle around with this thing on the basis of people's philosophy and politics and all the rest of it while these tragedies occur.

I want to, number one, thank the Rays for telling their story, and thank Dr. Barbosa, a man medicine, for laying it out just plain, simple, no ifs, ands or buts as to what needs to be done, what the risks are I also want to thank you Counselor for your comments as to just how helpful the "representatives" of the people have been in this particular instance and others like it.

Thank you, Mr. Chairman.

The **CHAIRMAN**. Thank you very much. I want to give the assurances to the Ray family that, as Senator Weicker has pointed out so well, this is not a partisan issue. We have bipartisan support for our original bill, and bipartisan support for the legislation that we have on discrimination and confidentiality. I certainly join in the call for early action, and I think your presence here today will hopefully speed that process.

Senator Metzenbaum.

Senator **METZENBAUM**. Mr. and Mrs. Ray, the thing that has concerned me as much as anything in this entire matter, and I share the concerns of those who have spoken before me, but the part that is most bothersome, most hurtful, is the impact upon the children; because a ten-year-old, nine-year-old, eight-year-old, six-year-old, just normally have all sorts of little problems of growing up. Now, in this situation, they have problems getting into the school, and they get into school, make some adjustments, their home is burned down, you cannot turn to your pastor for some direction and support, you move the children into a motel, move them out of a motel.

Tell us if you would, either of you or both, about the children and what kind of special problems this has created for them.

Ms. **RAY**. It has been hard on the children. Up until this point, all of the children were in school. Our family was middle-class. We were doing fine. After this, the children have had problems such as nightmares. There have been incidents of bed-wetting, lots of fighting among themselves, which brothers and sisters normally fight but we are talking in excess over little things.

Mr. **RAY**. The oldest boy, he blames himself for the fire. We do a lot of talking with him. He just laid there several nights and just cried and said it was his fault that the house burned. And he said if he had not tested positive to the HIV virus that none of this would have happened, so it is his fault. These are some of the problems we have run into and had to deal with. I think now that he realizes that it was not his fault.

Senator **METZENBAUM**. It obviously was not his fault.

Mr. **RAY**. No, it was not.

Senator **METZENBAUM**. None of the other things that have occurred have been the children's fault.

Mr. **RAY**. I think he realizes that now. These are some of the problems we have had, psychological problems. They have talked to a psychologist out at All Children's in the past. She turned her statement over to the court. My wife read the statement. I have not.

Ms. **RAY**. Part of the thing is the week that these kids were in school in Desoto County, even under these, we might as well say, pressured circumstances, they felt better about themselves, they slept better, the fighting ceased. They felt like they were being accepted, that they were normal children again, which the only reason they are set apart is strictly because of a blood test. There is no signs, no symptoms.

What we are wanting to do is just get back into a normal life, settle back in, and just kind of, if it is ever possible, blend back into the woodwork so to speak. A lot of people say, well, why did you put your kids through this? It was like if we sat home, these kids were going to be under just as much pressure from being different. If you have to stay home all day, you get just a very minimum amount of education. They were only receiving three hours a week of education on home-bound.

Senator **Metzenbaum**. People have blamed you for wanting them to go to school?

Ms. **Ray**. Well, people blamed me because they say I am exploiting my children. The thing of it is we have had to do this. We sat quietly for five months and tried to work with our school board. We waited for them to come up with a policy, and they just continuously said, "We are working on it, we are working on it." And they still, I guess, as far as I know, have done nothing.

Mr. **Ray**. We even left the State of Florida trying to get away from the situation. We left the State of Florida and moved to Alabama and run slap into the same situation in Alabama. So upon finding we had to fight, we returned to our home. According to the local papers and stuff at that time, we had support from the local people there so we returned to fight our battle there in our home town, only to find that the politicians there rallied their people against it and caused more problems for us than we would have liked.

Senator **Metzenbaum**. What kind of work do you do, Mr. Ray?

Mr. **Ray**. I have got four years of correctional officer experience, and I have got semi-driving behind me.

Senator **Metzenbaum**. Has this created any problems for you in the workplace?

Mr. **Ray**. Yes. I am hesitant about going back into the correction field due to the harassment I could get from the inmates and prisoners from within the system. That has been my hesitance about going back into the correciton field. That is why I went into driving semi. I worked for a company that was in a county north of Desoto County for four weeks driving semi, hauling oranges and like that around. And when they moved and their business went into Georgia, hauling fruit and melons in Georgia, they asked me to come along with them. I had to decline due to the fact that we had a pending court case I had to be in Florida for. Since that time I have been unemployed.

Senator **Metzenbaum**. Has this wreaked havoc upon your own financial situation?

Mr. **Ray**. Yes, it is. It has wreaked havoc all the way around. I like to go out and work for what I get. I always have worked. Everything I have, maybe I have not had a lot, but I have not really asked for a lot. I like a simple life. What I made off of my income made me happy. Where I lived made me happy. And that is all I have wanted, just to be happy at what life I had. I have not asked for any more or any less than let me have a job, let me live, let me be happy at my level.

Senator **Metzenbaum**. Mr. Earl, do you practice in Arcadia?

Mr. **Earl**. No, sir. In fact, we have offices in Miami and Sarasota. My wife and I have been advised by lawyers in the area not to go to Arcadia any more. To understand this town and what has happened in this town, I think you have to go back to the 1960s in places like Philadelphia and Mississippi and Selma, Alabama. There is a blind hatred and an unwillingness to learn that truly is scary.

I went over to that town in the morning after the fire to pick this family up, and you could see the fear in their faces. I am not a civil rights lawyer. I am a land use and environmental lawyer. I got into this because my wife saw this story in the paper and Dr. Barbosa's story, and we said someone needs to help these people. What we got into here, I had no idea what this town and this whole situation was. It is truly scary.

Senator **Metzenbaum**. In Miami and Sarasota where you practice, it has not created any special problem, additional problems for you?

Mr. **Earl**. No sir. I think most people have called us and said somebody needs to do this, thank you, you are doing a good job, those sorts of things. Our clients and our fellow lawyers have expressed those thoughts.

Senator **Metzenbaum**. How about you, Dr. Barbosa? Where do you practice?

Dr **Barbosa**. In St. Petersburg, Florida, at All Children's Hospital. It is the Referral center for very sick children from the West Coast of Florida.

Senator **Metzenbaum**. And have you had any problems in your practice by reason of being the practitioner for the children?

Dr. **Barbosa**. No, I have not had any complaints from the people that work at the hospital. I have been told by people that work near Arcadia to stay out of Arcadia.

Senator **Metzenbaum**. To what?

Dr. **Barbosa**. To stay out of Arcadia.

Mr. **Ray**. I would like to say something. We have been talking a lot on the bad side of Arcadia. I would like to just say that there are some good people in Arcadia now. We do not want to downgrade the community to the extent that everybody there is bad. They are not. There are friends of ours still and people that have really been at a low profile but have supported us there in that community. If you read the Washington Post, the people against us call them low-life, but they are from all walks of life, and they are in that community there. There are good people in Desoto County and Arcadia. I would just like to make that known just because, you know, we are hearing the majority of the bad from the people because they have banded together and turned into such a storng group there. The ones that are in support of us are scared to stand up because they will be outcasts in the community and considered low-life. No matter what their standing is in the community now, they would not have a standing.

So let us just remember there are good people in Desoto County, too.

Senator **Metzenbaum**. Well, I think you both should know, and your children particularly should know, that I think the members of this Committee are very supportive of you and the problems you have experienced, and also share deep concern for the children. Some people may have created some problems for them, but a lot of members of the United States Senate are very much on their side.

Thank you, Mr. Chairman.

The **Chairman**. Thank you very much.

Senator Thurmond.

Senator **Thurmond**. Thank you very much, Mr. Chairman.

Mr. Chairman, I am deeply concerned over the AIDS question. I think sooner or later there has got to be some provision to have a person tested before blood can be given that could be used by another individual. It is just too dangerous.

I was pleased to be an original cosponsor of S.1220, the Omnibus Acquired Immune Deficiency Syndrome Act of 1987. That legislation has been unanimously reported out of this Committee and is now awaiting aciton by the full Senate.

However, I do have serious concerns about certain aspects of this particular legislation under consideration today. I believe this bill would establish a Federal right of action with significant penalties against those who are seeking to protect themselves from contracting AIDS. I question the wisdom of creating a Federal right for persons simply because they have a fatal and communicable disease.

I do think we need more information, and we ought to take every step we can to acquire more information and take every step we can to find a cure for AIDS and take every step we can to prevent AIDS. I will be glad to work along that line in any way I can.

I am very pleased to be here today, and I extend my deepest sympathy to this family. I can understand how they feel. I want to thank them for coming, and thank you, Mr. Chairman. That is all I have to say.

Mr. Chairman, I ask unanimous consent that my full statement be included in the record.

The **Chairman**. Your opening statement will be printed at an appropriate place in the opening pages of the record.

Senator Mikulski.

Senator **Mikulski**. Thank you very much, Mr. Chairman, and to the Ray family and those who have helped them. I think what the testimony very clearly points out is that we have two national challenges. One is the manage the disease itself, to find a cure, to provide care and to contain its spread through public education. But the other is equally as challenging, to manage the fear around the disease. Because you are doubly victimized, testing positive for an antibody that your children have, that you wonder what is going to happen to them. But now you are coping not with the disease but with the insidious thing that has happened to your family as a result of the fear of the disease.

I think what it points out, as Mr. Ray said, not everybody in Arcadia is bad. We are not here to bash Arcadia because I think if you lived in any community, the way the fear is not being managed, would have happened everywhere. Dr. Barbosa said what he called the medical community, they responded. I am delighted to hear that CDC and other Federal agencies were so prompt and so helpful. But then when he turned to the people who were supposed to help the families, the social agencies, that they were not there to help you.

I think it points out two things: One, that we have no clear national policy, and you have the Surgeon General of the United States saying one thing and reaching out his hand to a fellow physician; but you have a Secretary of Education saying another, and a President of the United States who is silent. Perhaps when the Pope and the President met each other in Miami, they should have taken a ride to Arcadia to preach the message of democracy and of the faith I happen to espouse.

Having said that, I think we now have to go on to how we can manage that fear and that disease. We have one bill pending. We're exploring another which goes to the point of testing, Doctor. I think the Rays have spoken eloquently, and, Mr. Earl, I am glad you took the initiative of representing the family here. Certainly, Legal Aid would not have been allowed to do it with our new rules.

But, Doctor, I want to talk about testing. One, if you could tell me a couple of things which deal with testing and the safety of the blood supply. When you tested these little boys, did they have the full extent of the testing, the first test, the second test, the third test, the confirming test?

Dr. Barbosa. Well, we have the so-called ELISA test that is the preliminary test. If that is positive, we go to a confirmatory test that is called the Western Block test. Yes, they had all the tests on several occasions.

Senator Mikulski. So they have had the Western Block. In other words, you went through the whole process so that you knew that there was no error.

Dr. Barbosa. That is correct.

Senator Mikulski. And that one of the things that you would insist upon in any testing is that the complete verification process go on.

Then did you counsel the Rays as to what occurred? Because there is so much talk about counseling.

Dr. Barbosa. Absolutely. We talked about the implications of having a positive test. We talked about the possibility of developing AIDS.

By the way, I want to make it very clear here that we are dealing with a population that is somewhat different from the other high-risk population of developing AIDS. We are talking about the hemophiliac population. We have about 20,000 hemophiliacs in this country. Ten thousand of them, or 50 percent, are severe hemophiliacs. Ninety-five percent of those severe hemophiliacs are positive for the HIV.

But for reasons that we do not know, only 3.1 percent of the hemophilia population that is positive for HIV has gone and developed the full-blown picture of AIDS as compared with 30 or 50 percent of the other high-risk population.

Senator Mikulski. Doctor, when you said in your testimony the boys took the test and, as expected, they tested positive, "as expected" caught my attention. Now, you are saying that. Why are they testing positive? Is there something wrong with the safety of the blood supply that is keeping them alive?

Dr. **Barbosa**. Until two or three years ago, we did not have any means to screen blood donors. Each vial of Factor VIII concentrate or the anti-hemophiliac factor that we use to treat bleeding episodes in hemophiliacs comes from a pool of 10,000 to 20,000 donors, thus the likelihood of being infected is pretty high.

Senator **Mikulski**. Do you now feel that we are taking the test to assure the safety of the blood supply? As you know, many people are very apprehensive about surgery because of the blood supply. As a physician, and perhaps you would like to elaborate on the scientific community, where are we in terms of the safety of the blood supply?

Dr. **Barbosa**. Well, I believe that the chances of getting AIDS or HIV positivity from a blood transfusion are one in 50 or a hundred thousand right now, because that there is a window period where somebody can be exposed to the virus, and it takes from two to twelve weeks for that person to develop the antibody and test positive. In the meantime, that person may be testing negative when that person is donating the blood.

But getting back to the hemophilia situation, that is not the case. Blood donated for preparation of the Factor VIII concentrate is already screened and heat treated, a procedure that kills the HIV. Thus the product that we are now using, specifically for hemophiliacs, is one hundred percent safe as far as the AIDS virus is concerned.

Senator **Mikulski**. So the hemophiliac products are safe, and steps are being made to ensure the safety of the blood supply.

Dr. **Barbosa**. That is correct.

Senator **Mikulski**. But there is still risk.

One last area of questioning about education. Mr. and Mrs. Ray, when your children were at home for that year, what type of education did they receive? Was there call-ins? Were books brought by? Were there lesson plans? What was done to kind of help them keep up? I know it is hard to get a fourth and fifth grade to sit at any table long enough to go over a lesson plan. But even though they were being essentially under educational house arrest in their own community, what was being visited?

Ms. **Ray**. They had a homebound teacher who came to the house three days a week. The teacher stayed for three hours, which meant each child had one hour of schooling. That was a total of three hours a week.

During this time, you know, I was asking the teacher how are they doing. "They are doing fine. They are on grade level. They are doing super." And the kids, the papers they were showing me were good grades.

When we moved to Alabama for the short period of time and the boys started school, after the second day of school I started getting notes: Why are your boys so far behind? One thing in particular I can remember about Robert, why isn't he writing in cursive? We have been doing it since before Christmas. Then I started getting phone calls.

That showed me just how far behind these children were. They were not receiving enough, not nearly enough.

Senator **Mikulski**. So what you are saying is no one came by and said, "Mr. and Mrs. Ray, we have got a tough problem here. We do not know how to handle it, essentially because of the fear"?

Ms. **Ray**. I almost felt like we were just kind of swept under the carpet, and this was something just to appease us and to keep us quiet.

Senator **Mikulski**. But they did not come by and say, "We do not know what to do, but we do not want to turn our back on your boys; and, therefore, we are going to bring in the lesson plans and maybe you need to get a home computer to keep them up to date"? No tips, no advice, no involvement, and no personal support?

Ms. **Ray**. They did not even have home work.

Senator **Mikulski**. I think I have got a better picture, and I certainly hope 1988 is a better year for you. But it shows we have got a lot of our own home work to do.

Ms. **Ray**. That is the reason we came. We are hoping that what we have gone through is going to make America open their eyes and say, you know, this family could have been us; we need to join together and try to help each other rather than turning our backs and being afraid. I think the biggest problem is that people are not educated.

Two years ago, I had a chance to send my boys to hemophilia camp, and I did not know anything about AIDS but this was during the time when the story about Ryan White was so big. I refused to let my kids go because I did not want them to catch AIDS. And I am ashamed of myself for that now. The thing of it is I went out and I learned. I learned how it is transmitted. I learned about the myths and what they are.

It makes a big difference. I think if we could get that across to the general public and educate them, you would see a big turnaround. Not only would you see compassion, but I believe that you would see this disease start to fizzle out. I really do because people would learn how to control it.

The **Chairman**. We want to thank you again for coming here. I must say this last comment is very revealing, and certainly hopeful the fact that you are willing to acknowledge your own misconception about AIDS and its transmission. Yet your understanding of this now challenges, the country, perhaps even the world, to develop a greater sense of compassion and understanding.

I must say, Mr. Ray, I admire your willingness to speak of your friends back in Arcadia. I thought that was rather touching. I thought Senator Mikulski stated it well when she said that no one is interested in bashing Arcadia, but at least in the course of the question and answer, one could certainly draw the conclusions that there are some people who have not received the education and not tapped into the understanding or the generosity of spirit which hopefully exists in all of us. I think your speaking out in defense of some of your friends and neighbors and talking about that occasion took some guts, particularly after what your family has experienced. I am not sure that many people would be as willing to make that comment.

I am hopeful that you will receive greater sense of compassion and understanding in your future. I think you have laid down the challenge for us in the Congress, the Senate. Many of us are prepared to take up that challenge. I think that is probably the best way that we can express our appreciation for your presence here.

I want to thank Mr. Earl, who is a great credit to the legal profession, and Dr. Barbosa, who is a great credit to the medical profession. We want to thank all of you, and we will excuse you at this time.

We will have a minute recess.

[Recess.]

The **Chairman**. We will come to order.

Our next panel is Alberta Fuentes from the Commission on Human Rights of NYC, and Katy Taylor from the AIDS Discrimination Unit, Commission on Human Rights, the City of New York. That is the commission established by the city to deal with discrimination. We are very grateful for their testimony and their presence.

We have taken a good deal of time with our earlier panel, and we do not want to indicate that the comments that we are going to have later during the course of this hearing are less important. But we are going to try and move the hearing along. We have got some questions, so we will ask our witnesses if they would try and keep their comments brief, but we are also interested, obviously, in the substance of their presentation.

So we will proceed with Ms. Fuentes.

## STATEMENT OF ALBERTA A. FUENTES, COMMISSION ON HUMAN RIGHTS, CITY OF NEW YORK; AND KATY TAYLOR, AIDS DISCRIMINATION UNIT

Ms. **Fuentes**. Thank you, Mr. Chairman and fellow Committee members.

I am Alberta Fuentes, and I represent the New York City Commission on Human Rights. I am here today to talk to you about HIV-related discrimination and the need for Senate Bill 1575, the AIDS Federal Policy Act of 1987. I hope to offer a unique perspective on the phenomenon we have come to call the Second Epidemic—that of fear, misinformation and prejudice surrounding AIDS.

The scope of HIV-related discrimination is often devastating. One of the first calls the Commission received was from a Hispanic woman from the South Bronx who called the Commission to say that her daughter had died of AIDS-related complications, leaving behind three children. The woman had been unable to find a funeral home to deal with her daughter's body. We directed her to a funeral home willing to handle the bodies of those who died of AIDS-related complications. After the fact, the woman decided she could not face a formal complaint against the original funeral director. She felt the experience was behind her and did not want to delve back into painful memories.

Approximately a year-and-a-half later, the same woman had to call us again. She had tried to find someone who would care for her grandchildren without success. No one would accept the offspring of a person who had AIDS. The children had come to live with her in an already crowded apartment. Now, she reported, the landlord had found out the cause of her daughter's death and wanted to evict her and the three healthy grandchildren. Through a series of phone calls, we stopped the eviction.

Last fall, a black woman telephoned the Commission to complain that her 9-year-old daughter was expelled from a private school because the principal learned that the child's aunt had AIDS and lived with them. The school was afraid that other parents would pull their children out of the school if they found out about this. The Commission investigated the complaint and found probable cause to support the allegation of discrimination. A public hearing on this case has been scheduled.

These are not unusual stories. This is the sort of treatment accorded people with AIDS and anyone suspected of being HIV-infected.

In New York City, we have seen a phenomenal rise in the number of AIDS- and HIV-related discrimination complaints. The AIDS Discrimination Unit was formed was in 1983 and remains one of the few units or agencies dealing with AIDS stigma. So far we have received over 800 complaints of HIV-related discrimination. In 1986, 314 complaints were brought to the agency, an increase of more than 300 percent over 1985. And in the first six months of this year, the unit has already received over 300 complaints. Thus, we can expect at least 600 complaints this year. This trend shows no indication of stopping; as the number of AIDS diagnoses climbs, so do the number of AIDS discrimination complaints.

Over two-thirds of our cases are from people with AIDS. Already burdened by often debilitating disease, hundreds of people have told us about their experiences being thrown out of their homes; about being refused medical care; and being fired from jobs because their co-workers or bosses were uncomfortable with AIDS. We have also received reports about children barred from both public and private schools. And we have received scores of reports of AIDS-related bias and violence, such as you heard today: beatings, bomb threats, even attempted murder. It seems that, sadly, AIDS-based violence must be added to the list of hate crimes which plague our communities.

But people with AIDS are not the only victims of AIDS-related discrimination. One-third of our complaints are brought by people who do not have AIDS but who were perceived to have AIDS because they are members of a so-called "risk group" or are HIV-antibody positive. Service providers, family members and loved ones of people with AIDS have also been subjected to AIDS-related discrimination. Initially, people were categorized on the basis of risk group rather than risk behavior. The focus was placed on who you are rather than on what you do. Yet it is how we do what we do—unprotected sexual intercourse, shared intravenous needles, et cetera—that is the significant factor in HIV transmission. This misperception causes tremendous discrimination against people assumed to be risk group members.

To cite just one example of AIDS backlash on an identifiable group, consider the devastating impact of AIDS-related discrimination on Haitians. Despite the fact that Haitians have been removed from the CDC's list of AIDS risk groups, the stigma remains. Haitian children have been beaten up and, in at least one case, shot in school; Haitian store owners have gone bankrupt as their businesses failed; and Haitian families have been evicted from their homes. The problem of discrimination against this community is not new, but unfounded fears against AIDS have surely escalated the intensity of prejudice directed against Haitians.

The World Health Organization and the New York City Department of Health have revised their risk categories to more precisely reflect risk behavior. Given the nature of the AIDS epidemic, good public health policy must incorporate civil rights protections, or the epidemic will be driven further underground. Where widespread stigmatization and discrimination exist, all people are understandably reluctant to seek needed information, diagnosis and treatment. Public health and civil rights are necessary allies in the fight against AIDS. Therefore, anti-discrimination protections are appropriately included with the HIV-antibody testing and confidentiality provisions of the AIDS Federal Policy Act.

We must acknowledge that there are co-factors of discrimination. Discrimination does not exist in a vacuum. It has both a history and a social context. For many people, among them minorities, women and the poor, AIDS-related discrimination is the latest chapter in a history of discrimination on the basis of race, gender, economic class and, in some cases, sexual orientation.

In our recent report entitled "AIDS and People of Color: The Discriminatory Impact," we point out that in New York City 55 percent of the people with AIDS are black or Hispanic. As of June 24, 1987, women constituted 10.4 percent of the reported AIDS cases in New York City. Out of this total, 84 percent are women of color. Nationally, the number of cases of women with AIDS reported to the Centers for Disease Control has increased more than 15-fold from 162 at the end of 1983, to 2,569 as of July 1987. It is projected that by 1991 AIDS will be the largest killer of women of child-bearing age in New York City.

Between June 1981 and July 1987, 525 cases of children with AIDS ages 0 to 12 were reported to the National Centers for Disease Control. Of this number, 414 are children of color. In New York City, there are 187 children known to have AIDS; 90 percent are black or Hispanic. Consequently, these communities hardest hit by AIDS discrimination are often the least likely to "trust the system" and may not seek help when confronted with AIDS-related discrimination.

The CHAIRMAN. I will give you another couple minutes to wind up.

Ms. FUENTES. It must be remembered that race, gender, class and similar factors have often been important in determining who has access to education, health care and the media. In the face of overwhelming stigma, too many people at risk for discrimination simply do not know what their basic civil rights are relative to AIDS.

The bottom line is that the epidemic of AIDS stigma and discrimination continues to grow. By enacting this proposed legislation, the Federal Government will send a much needed message to all communities: HIV-related discrimination is illegal and will not be tolerated.

Thank you.

[The prepared statement of Ms. Taylor follows:]

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ALBERTA B. FUENTES, *Executive Director*

## THE SECOND EPIDEMIC

**Testimony of the**
**NYC Commission on Human Rights'**
**AIDS Discrimination Unit**

by

Katy Taylor
Deputy Director of the
AIDS Discrimination Unit

before the Senate Committee
on Labor & Human Resources

Bill S.1575
AIDS Federal Policy Act of 1987

September 11, 1987

Mr. Chairman and fellow committee members. I am Katy Taylor and I represent the AIDS Discrimination Unit of the NYC Commission on Human Rights. I am here today to talk to you about HIV-related discrimination and the need for Senate bill 1575, the AIDS Federal Policy Act of 1987. I hope to offer a unique perspective on the phenomenon we have come to call the Second Epidemic - that of fear, misinformation and prejudice surrounding AIDS.

The scope of HIV-related discrimination is often devastating. One of the first calls the Commission received was from a Hispanic woman from the South Bronx who called the Commission to say that her daughter had died of AIDS-related complications, leaving behind three children. The woman had been unable to find a funeral home to deal with her daughter's body. We directed her to a funeral home willing to handle the bodies of those who died of AIDS-related complications. After the fact, the woman decided she couldn't face a formal complaint against the original funeral director. She felt the experience was behind her and didn't want to delve back into painful memories.

Approximately a year and a half later, the same woman had to call us again. She had tried find someone who would care for her grandchildren without success. No one would accept the offspring of a person who had AIDS. The children had come to live with her in an already overcrowded apartment. Now, she reported, the landlord had found out the cause of her daughter's death and wanted to evict her and the three healthy grandchildren. Through a series of phone calls, we stopped the eviction.

Last fall a Black woman telephoned the Commission to complain that her 9 year old daughter was expelled from a private school because the principal learned that the child's aunt had AIDS and lived with them. The school was afraid that other parents would pull their children out of the school if they found out about this. The Commission investigated the complaint and found probable cause to support the allegation of discrimination. A public hearing on the case has been scheduled.[1]

These are not unusual stories. This is the sort of treatment accorded people with AIDS and anyone suspected of being HIV-infected.

In New York City, we have seen a phenomenal rise in the number of AIDS- and HIV-related discrimination complaints. The AIDS Discrimination Unit was formed in 1983 and remains one of the few units or agencies dealing with AIDS stigma. Because of the nature of this crisis, our work has required national cooperation. So far we have received over 800 complaints of HIV-related discrimination. In 1986, 314 complaints were brought to the agency - an increase of more than 300% over 1985. And in the first six months of 1987, the unit has already received over 300 complaints. Thus we can expect at least 600 complaints this year alone. This trend shows no indication of stopping; as the number of diagnoses climbs, so do the number of AIDS discrimination complaints.

Over two thirds of our cases are from people with AIDS. Already burdened by an often debilitating disease, hundreds of people have told us about their experiences being thrown out of their homes; about being refused medical care; about being fired from jobs because their co-workers or bosses were uncomfortable about AIDS. We have also received reports about children barred from both public and private schools. And we have received scores of reports of AIDS-related bias and violence - beatings, bomb threats, even attempted murder. It seems that, sadly, AIDS-based violence must be added to the list of hate crimes which plague our communities.

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[1] For an expanded description of the types of complaints we have received, I refer you to our two AIDS Discrimination Reports. The first, dated April 1986, details the first 170 complaints received by the Unit. The second, dated August 1987 focuses on representative complaints received from January 1986 through July 1987.

But people with AIDS are not the only victims of AIDS-related discrimination. One-third of our complaints are brought by people who do not have AIDS but who were perceived to have AIDS because they are members of a so-called "risk group" or are HIV-antibody positive. Service providers, family members and loved ones of people with AIDS have also been subjected to AIDS-related discrimination. Initially, people were categorized on the basis of risk group rather than risk behavior. The focus was placed on who you are rather than on what you do. Yet it is how we do what we do (unprotected sexual intercourse, shared intravenous needles, etc.) that is the significant factor in HIV transmission. This misperception causes tremendous discrimination against people assumed to be members of these risk groups.

The World Health Organization and the New York City Department of Health have revised their risk categories to more precisely reflect risk behavior. Given the nature of the AIDS epidemic, good public health policy must incorporate civil rights protections or the epidemic will be driven further underground. Where widespread stigmatization and discrimination exist, all people are understandably reluctant to seek needed information, diagnosis and treatment. Public health and civil rights are necessary allies in the fight against AIDS. Therefore anti-discrimination protections are appropriately included with the HIV-antibody testing and confidentiality provisions of the AIDS Federal Policy Act.

To cite just one example of the AIDS backlash on an identifiable group, consider the devastating impact of AIDS-related discrimination on Haitians. Despite the fact that Haitians have been removed from the CDC's list of AIDS risk groups, the stigma remains. Haitian children have been beaten up (and in at least one case, shot) in school; Haitian store owners have gone bankrupt as their businesses failed; and Haitian families have been evicted from their homes. The problem of discrimination against this community is not new, but unfounded fears about AIDS have surely escalated the intensity of prejudice directed against Haitians.

## Acknowledging the Co factors of Discrimination

Discrimination does not occur in a vacuum. It has both a history and a social context. For many people, among them minorities, women and the poor, AIDS-related discrimination is the latest chapter in a history of discrimination on the basis of race, gender, economic class and, in some cases, sexual orientation.

In our recent report entitled AIDS and People of Color: The Discrminatory Impact (revised, August, 1987), we point out that in New York City 55% of the people with AIDS are Black or Hispanic. As of June 24, 1987, women constituted 10.4% (1096) of the reported AIDS cases in New York City; out of this total, 84% are women of color. Nationally the number of cases of women with AIDS reported to the Centers for Disease Control has increased more than fifteenfold from 162 in the end of 1983, to 2569 as of July, 1987. It is projected that by 1991 AIDS will be the largest killer of women of childbearing age in New York City. Between June 1981 and July, 1987, 525 cases of children with AIDS (ages 0-12) were reported to the National Centers for Disease Control. Of this number 414 (79%) are children of color. In New York City there are 187 children known to have AIDS - 90% are Black or Hispanic. Consequently, those communities hardest hit by AIDS discrimination are often the least likely to "trust the system" and may not seek help when confronted with AIDS-related discrimination.

It must be remembered that race, gender, class and similar factors have often been important in determining who has access to education, health care and the media. In the face of overwhelming stigma, too many people at risk for discrimination simply do not know what their basic civil rights are relative to AIDS.

The bottom line is that the epidemic of AIDS stigma and discrimination continues to grow. By enacting this proposed legislation, the [redacted]ge to all communities: **HIV-related discrimination is illegal and will not be tolerated.**

## EMPLOYMENT

In the last year, many personnel officers and law firms representing employers have contacted the Commission and requested assistance in formulating rational, nondiscriminatory policies regarding AIDS. Despite this trend, employees -- particularly those in jobs with a great amount of client contact (e.g. restaurants, hotels, transportation) -- continued to report AIDS-related discrimination.

Many incidents result in termination. Lack of accurate information about the syndrome often prompts irrational reactions from co-workers and employers alike. Mere mention by a seemingly healthy individual of involvement with someone who has AIDS can lead to the loss of employment. Employers, hoping to avoid any disruption of the work environment, often terminate employees with AIDS to pacify frightened staffmembers.

To summarize a few of the employment complaints: An Hispanic instructor for a beauty school with AIDS was denied the right to return to work when his health stabilized. The school initially claimed there was a hiring freeze but subsequently admitted that they refused to permit the man to return to work because of his AIDS condition. A hearing has been scheduled. In another case a nurse in a private hospital was contemplating becoming pregnant and requested the HIV antibody test offered by her employer. She submitted to the test after receiving repeated assurances that the results would be absolutely confidential and have no effect on her employment, . When she tested positive, confidentiality was immediately violated and she was unilaterally transferred from her position. The Commission is still attempting to resolve the situation.

HOUSING

Some of the most devastating discrimination reports brought to the Commission involve housing. In such cases, not only does the person with AIDS have to cope with a swift decline in health but the individual also must face the possibility of having nowhere to live during this crisis. Landlords have been charged with refusing to make repairs or provide essential services, such as interrupting heat and hot water (life-threatening factors for those in poor health) and harassing people with AIDS in an attempt to illegally evict them from their apartments.

One Manhattan tenant with AIDS reported that the landlord and his agents subjected him and his two neighbors with AIDS to many offensive tactics. The handyman assaulted and threatened two tenants in the building. When the police were called the handyman tried to discredit the tenant by saying, "Don't believe him, he has AIDS."

The wife of a man with AIDS called to say that due to the landlord's fear of AIDS, her heat and hot water had been turned off by her landlord in an effort to drive the family out. She only wanted the services restored and did not have the time to devote to a discrimination complaint.

The Commission has also received complaints of discrimination in the rental of commercial space. An organization attempting to establish a national AIDS hotline signed a lease with a realty company for office space. The realtor denied the tenants the keys explaining that other tenants objected to the presence of an AIDS-related group in the building. The Commission intervened and the AIDS hotline director was then able to negotiate with the landlord to obtain suitable office space. Medical professionals (doctors, dentists and laboratories) have also reported termination of their leases or refusal to rent when it becomes known that their patients include persons with AIDS.

Combatting discrimination against people with AIDS is not only good public health in action - it is also cost effective government. When an individual is prevented from returning to his place of employment because of fear of AIDS, he is not only denied a job, but also loses his insurance and frequently defaults on his rent. As a result, governmental bodies, in all their forms, will bear the brunt of costs incurred for this individual.

HIV-related discrimination has permeated every aspect of our society. Section 504 of the Federal Vocational Rehabilitation Act offers protection to people with disabilities - in this case, AIDS - who are either employed by the federal government or employed by an entity funded by the federal government. Yet our work has shown that existing state and local statutes prohibiting disability discrimination are uneven and unevenly enforced, leaving many people with AIDS without protection. Much more is needed to oppose the virulent discrimination in the private sector directed toward anyone connected with this disease. This proposed legislation is, however, an important and necessary step toward insuring that HIV-discrimination is eliminated from our society. I urge you to favorably consider this vital piece of legislation.

Thank you for your time. I am available for further discussion and to answer any questions you may have. Also, I have available for your review, two reports which the Commission on Human Rights has produced. The first is entitled "A Report on Discrimination Against People With AIDS" and the second, a report on the effect of AIDS upon minorities, is entitled "AIDS and People of Color, The Discriminatory Impact."

The CHAIRMAN. Thank you very much. It is very helpful in pointing out the importance of adopting some important guidelines or ordinances in terms of the city. I think you would have to conclude that they have been helpful. I suppose a great part of this is education so that the victims themselves know their rights. I suppose that this is always a problem, is it not?

Ms. FUENTES. It certainly is. As well as the victims knowing their rights and having access to a cause of action, it is very, very important.

The CHAIRMAN. Counseling and for them to know and know where to go and know how to get help and alert the Commission to provide some help and assistance.

Ms. FUENTES. That is very important, but it is also important that the public at large is educated because a lot of the discrimination that occurs is due to ignorance.

The CHAIRMAN. We have, as you know, two pieces of legislation: one is an education provision in terms of the research program and the counseling and of the help and support for health personnel, at-home services, foster care, and other kinds; then the others, which we are primarily concerned with today in terms of testing and confidentiality and discrimination. They are obviously intertwined in terms of the education. What we are focusing on today is confidentiality and discrimination.

I suppose one of the very perplexing problems that you face is where you get complaints that are legitimate and that have violate the city ordinance, and yet is the defendant in the case strings the case along without final resolution. I imagine, in some instances, they hope they will not have a final result because death will intervene. Do you find that this is the case?

Ms. FUENTES. This is Katy Taylor. She is the Deputy Director of the AIDS Discrimination Unit at the Commission.

Ms. TAYLOR. That is enough of a problem that we have adopted a typical way of handling AIDS discrimination cases which is on an expedited basis because we were told directly, frequently by attorneys, that their tactic was to delay in the hopes that the complainant would simply die and that would be the end of it.

We have done a number of things to try and counteract that; for instance, to secure money so that we could depose any potential witness in a hearing that would come up.

The CHAIRMAN. Does that help? Does that make a difference?

Ms. TAYLOR. Yes. It has definitely made a difference, but I think the most important thing is to have a very prompt and immediate response and an expedited case investigation. But I think that probably the most important thing has been the very public and prominent stance that the Commission has taken against discrimination.

Ms. FUENTES. In addition, there has been a court ruling in the funeral home cases that we had gone into court on that the family of the deceased in certain instances could continue the case or file cases on their own.

The CHAIRMAN. Well, I think you make a strong case in support of the type of legislation that we have developed and introduced. It is obviously going to take fine tuning as we move through this significant area of public policy. We are most interested in what is happening on the front lines, in areas like New York that are trying to deal with issues of confidentiality and anti-discrimination.

We want to work very closely with you as we work through this legislation, and we appreciate very much your cooperation.

Let me ask, how important is the existence of New York State and New York City laws and ordinances in assisting your efforts to overcome these problems?

Ms. **Taylor**. I would say that they have been essential. We are fortunate in New York in that we do have fairly comprehensive statutes, and we also have adopted a broad interpretation; and I think most importantly we have support for enforcement.

But this is not the case in a lot of places. I know that because we have from the beginning received calls from around the country and have been something of a resource for other parts of the country trying to deal with this. But even with that, we still spend an enormous amount of our time dealing with jurisdictional challenges. Even with the laws that we have, there are still numerous omissions and loopholes.

The **Chairman**. Do you believe that Federal legislation will strengthen your efforts?

Ms. **Taylor**. Absolutely. There is no question about it.

Ms. **Fuentes**. Definitely.

Ms. **Taylor**. I would say that it is critical for a variety of reasons, particularly as we move toward increasing use of the tests because there is so much confusion about transmission. Testing is a major factor in our discrimination cases, and I think we will see even more of that unless there is some strong anti-discrimination posture from the Federal Government.

I think that it also supplies an important educational message about discrimination, both that it is illegal and will not be tolerated, and it lends sort of a moral position that is much, much needed. It lends leadership on this issue that has been lacking at practically every level, particularly on the discrimination issues.

The **Chairman**. I think that is a very helpful comment by the panel that obviously has been working on this and understands the real needs.

I want to thank you very much. You have been very, very helpful.

Ms. **Fuentes**. I have just one thing to say following up on what Katy said.

The **Chairman**. Fine.

Ms. **Fuentes**. Combatting discrimination against people with AIDS is not only good public health in action; it is also cost effective government. When an individual is prevented from returning to his job for fear of AIDS, he is denied not only a paycheck but insurance, and frequently defaults on his rent. As a result, governmental bodies in all of their forms bear the brunt of those costs incurred as a result of that discrimination. So we have got to look at it from moral as well as financial respects.

The **Chairman**. That always seems to be the bottom line, and we hear an awful lot about it around this town. But even when you are able to show it is difficult to get a positive response. But I think it is an important point to make. We want to thank you both very, very much for your appearance here today.

Ms. Fuentes. Thank you.

Ms. Taylor. Thank you.

The Chairman. Our next panel is Lonnie Bristow, member of the Board of Trustees, American Medical Association, Chicago, Illinois; Mary Foley, Chairperson, Cabinet on Economic and General Welfare, American Nurses Association, Washington, D.C. I would ask both of them if they would be kind enough to come up.

We are glad to have you both, and we look forward to your testimony. We will start with Lonnie Bristow. Please begin.

## STATEMENTS OF LONNIE R. BRISTOW, M.D., MEMBER, BOARD OF TRUSTEES, AMERICAN MEDICAL ASSOCIATION, CHICAGO, IL, ACCOMPANIED BY MICHAEL ZARSKI; AND MARY FOLEY, B.S.N., R.N., CHAIRPERSON, CABINET ON ECONOMIC AND GENERAL WELFARE, AMERICAN NURSES ASSOCIATION, WASHINGTON, DC, ACCOMPANIED BY DONNA RICHARDSON AND TOM NICHOLS

Dr. Bristow. Thank you, Mr. Chairman.

My name is Lonnie R. Bristow, a physician in the practice of internal medicine in San Pablo, California. I am also a member of the Board of Trustees of the American Medical Association. With me today is Mr. Michael Zarski, a member of the Association's Division of Legislative Activities.

The AMA truly appreciates this opportunity to appear before the Committee to express our views on Senate Bill 1575, the AIDS Federal Policy Act of 1987.

We are pleased with the introduction of this legislation which provides for AIDS testing and counseling. We feel this legislation is an example of a reasoned public health response to the problem of AIDS, and it is consistent with many statements of AMA policy on this particular issue. It is our hope that the Congress will not delay in providing the necessary funding for voluntary testing along with the attendant confidentiality protections.

The AMA fully supports Part A of the AIDS Federal Policy Act, which is the part, of course, which provides for a $400 million Federal grant program to test individuals for HIV and to counsel them about AIDS prevention, transmission, and the availability of health services. These counseling requirements, we believe, are essential to any testing program. Because there is no cure for AIDS, the best efforts for reducing the spread of the disease involve modifying the behavior of individuals through education and counseling.

Part B of the AIDS Federal Policy Act contains the basic protections for information obtained from testing, counseling or the deriving the diagnosis of AIDS. This information is generally protected from disclosure by anyone who may be involved in the process of counseling or testing or who may see the records of such counseling or testing.

Although there is a duty to maintain confidentiality, we believe that duty is not absolute. In certain circumstances where there is a realistic potential threat to another's life, the interests of a third party or of society as a whole should prevail over absolute confidentiality. These circumstances are treated as the exceptions to the confidentiality protections of Part B. The AMA supports the inclusion of these narrow exceptions to the general requirements of confidentiality.

We strongly oppose discrimination based on a person's health status. We are pleased to have had a role in diminishing the threat of unreasoned discrimination in the recent U.S. Supreme Court case of the School Board of Nassau County, Florida v. Arline. The Supreme Court's opinion in this case established that under Section 504 of the Rehabilitation Act, a person with a contagious disease may be considered a "handicapped individual" subject to protection from discrimination by employers' prejudiced attitudes, stereotypes or unfounded fears. The Supreme Court made reference to, with its approval, the AMA's position that employment decisions about persons with contagious disease should be based on reasonable medical judgments, given the state of medical knowledge about the disease and the associated risks, with particular reference to the nature of the risk, the duration of the risk, the severity and the actual probability of risk.

As you have heard, we also were fortunate enough to participate in the Ray case that was presented before the Committee earlier. We believe strongly that allowing irrational discrimination against those with AIDS or who are HIV positive serves no useful purpose. Federal and state laws which prohibit discrimination against the handicapped provide an appropriate framework for enforcing protection for such individuals.

It is essential, however, that the language of Part C be interpreted as being consistent with the existing protections of civil rights law. The AMA also believes that the Supreme Court's analysis in the Arline case deserves to be incorporated in this bill. The AMA would be pleased to work with the Committee to improve the effect of Part C of this legislation.

In conclusion, we believe there are no easy answers to many of the pressing issues involving AIDS. The members of Congress have obviously introduced a variety of measures with the best of intentions—that of quickly rendering AIDS a public health threat of the past, just as smallpox and polio have become. We commend all members of Congress who have concerned themselves with this critical issue.

We are pleased that Senate Bill 1575 is so similar to many of the recommendations contained in a recent report adopted by the AMA House of Delegates. This bill, we believe, provides important services and approaches to deal with the very complex problems of AIDS.

Mr. Chairman, Mr. Zarski and I will be pleased to answer any questions that you may have.

[The prepared statement of Dr. Bristow follows:]

# STATEMENT

of the

AMERICAN MEDICAL ASSOCIATION

to the

Committee on Labor and Human Resources
United States Senate

Presented by

Lonnie R. Bristow, M.D.

RE: S. 1575—The AIDS Federal Policy Act of 1987

September 11, 1987

Mr. Chairman and Members of the Committee:

My name is Lonnie R. Bristow, M.D., and I am a physician in the practice of internal medicine in San Pablo, California. I am also a member of the Board of Trustees of the American Medical Association. With me is Michael J. Zarski of the Association's Division of Legislative Activities.

The AMA appreciates this opportunity to appear before the Labor and Human Resources Committee to express our views on the AIDS Federal Policy Act of 1987.

We are pleased with the introduction of this legislation which provides for AIDS testing and counseling. This legislation is an example of a reasoned public health response to the problem of AIDS and is consistent with many statements of AMA policy on this issue. We hope that Congress will not delay in providing the necessary funding for voluntary testing along with attendant confidentiality protections.

Testing and Counseling

The AMA concurs with the U.S. Surgeon-General that "voluntary testing, easily accessible to all with appropriate counseling and with safeguards to ensure confidentiality, is good public health practice."

Individuals who know their HIV antibody status can take appropriate precautions to prevent infection of themselves if they are seronegative or to prevent transmission to others if they are seropositive. Physicians who know their patient's antibody status are able to evaluate the patient's condition, to counsel appropriately, and to determine proper medical management. Further, antibody test results could provide important information on the epidemiology of HIV infection in various populations and regions.

The AMA fully supports Part A of the AIDS Federal Policy Act. This part provides for a $400 million federal grant program to test individuals for HIV and to counsel individuals about AIDS prevention, transmission, and the availability of health services. These counseling requirements are essential to any testing program. Because there is no cure for AIDS, the best efforts for reducing the spread of the disease involve modifying the behavior of infected individuals through counseling.

Confidentiality

The threat of inappropriate disclosure of personal information, social ostracism and discrimination must be weighed against the advantages of testing and counseling. These factors must be considered when decisions are made as to whether HIV antibody testing should be mandatory or voluntary.

Regardless of the testing scheme, the AMA believes that standards of confidentiality are essential. Physicians already owe their patients a legal and ethical duty to maintain confidentiality in the physician/patient relationship. It is vital to an effective program of preventing and controlling AIDS for the health care community to maintain the confidentiality of patient information and restrict its use to only those purposes essential for maintenance of health.

Part B of the AIDS Federal Policy Act contains the basic protections for information obtained from testing, counseling or the diagnosis of AIDS. This information is generally protected from disclosure by anyone who may be involved in the process of counseling or testing or who may see the records of such counseling or testing.

Although there is a duty to maintain confidentiality, this duty is not absolute. The bill recognizes that, in certain circumstances, the interests of a third-party or of society should prevail over absolute confidentiality. These circumstances are treated as exceptions to the confidentiality protections of Part B. The AMA supports the inclusion of these narrow exceptions to the general requirements of confidentiality.

## Discrimination

The fear of AIDS stimulates discrimination against its victims and increases the risk of further spread of AIDS in the population by discouraging many who are at high risk from coming forward for screening. Jobs have been lost; AIDS victims have been evicted from apartments; school children have been expelled; and some victims have been ostracized even by their families. This discrimination threatens not only AIDS victims, but also threatens the collection of public health information needed to follow the epidemiology of AIDS.

The AMA is pleased to have had a role in diminishing the threat of unreasoned discrimination by filing an amicus brief in the recent U.S. Supreme Court case of School Board of Nassau County, Florida v. Arline. The Supreme Court's opinion in this case established that, under Section 504 of the Rehabilitation Act, a person with a contagious disease may be a "handicapped individual" subject to protection from discrimination by employers' prejudiced attitudes, stereotypes or unfounded fears. The Supreme Court cited with approval the AMA's position that employment decisions about persons with contagious disease, such as AIDS, should be based on reasonable medical judgments, given the state of medical knowledge about:

- o the nature of the risk (how the disease is transmitted);
- o the duration of the risk (how long the carrier is infectious);
- o the severity of the risk (the potential harm to others); and
- o the probabilities the disease will be transmitted and will cause varying degrees of harm.

A key question left open by the Supreme Court is whether a person who is not afflicted with AIDS or AIDS Related Complex (ARC), but who nonetheless tests positive for the HIV antibody, is protected by Section 504.

The Federal AIDS Policy Act would extend antidiscrimination protection to seropositive individuals. In addition, Part C of the Act goes beyond Section 504 which applies to recipients of federal funds, but generally prohibits discrimination in:

- o employment;
- o housing;

- o public accommodations; and
- o government services.

The AMA believes strongly that allowing irrational discrimination against those who are HIV positive serves no useful purpose. Federal and state laws which prohibit discrimination against the handicapped provide an appropriate framework for enforcing protection for seropositive individuals.

It is essential, however, that the language of Part C should be interpreted as being consistent with the protections afforded under current civil rights law. The AMA also believes that the Supreme Court's analysis in Arline regarding application of the rule of nondiscrimination deserves to be incorporated in this bill. The AMA would be pleased to work with the Committee and develop modifications to improve the effect of Part C of this legislation.

## Conclusion

There are no easy answers to many of the pressing issues involving AIDS. Members of Congress have introduced a variety of measures with the best of intentions--to render AIDS a public health threat of the past, like smallpox and polio. We commend all members of Congress who have concerned themselves with this critical problem.

We are pleased that the legislation before the Committee today-- the AIDS Federal Policy Act of 1987--is so similar to many of the recommendations contained in a recent report adopted by the AMA House of Delegates. It provides important services and policies to deal with the very complex problems involved in AIDS issues.

Mr. Chairman we will be pleased to answer any questions you may have.

3184p

The **Chairman**. Thank you very much. We will hear from Mary Foley now and then have questions.

Ms. **Foley**. Thank you, Mr. Chairman.

I am Mary Foley, Chairperson of the American Nurses' Association Cabinet on Economic and General Welfare. Today, I am accompanied by Donna Richardson and Tom Nichols from the ANA staff in the Washington office.

As a registered nurse in St. Francis Memorial Hospital in San Francisco, I provide care for the AIDS patients on an almost daily basis. Thank you on behalf of the 188,000 members of the American Nurses' Association for the opportunity to address this issue.

ANA recognizes that the AIDS epidemic has produced worldwide fear which has initiated emotional and sometimes irrational responses by the public, as well as by some state and Federal legislators and Government officials. As health care professionals, we believe it is our responsibility to advise the Congress regarding AIDS. The health care community must remain scientific, calm and logical regarding the prevention, management and care of the disease. We are distressed that some individuals have attempted to discount the existing scientific findings and recommendations made by our leading public health officials.

AIDS is a public health issue, not a moral or a political one. No groups know better than its victims and those who provide health care to them. Nurses see the devastation of this disease daily while giving care to AIDS patients and providing emotional support to their families and friends.

Therefore, Mr. Chairman, I would like to make the following points: Number one, carefully targeted educational programs and individual health counseling have been effective in combatting the transmission of AIDS and are the keys to minimizing the spread of AIDS. The HIV virus is transmitted through intimate sexual, blood-to-blood or body fluid contact. Overwhelmingly, the transmission of the disease can be effectively prevented by individuals abstaining from well-documented high risk behaviors.

As we all know, presently there is no cure for AIDS. It is a disease that is nursing intensive. Nurses provide continuous care during hospitalization, in the home, and during the hospice phase. Studies have shown that AIDS patients require almost double the amount of nursing time as equally ill patients who do not have AIDS. Accordingly, it appears that nurses bear a disproportionate amount of risk. However, a study to evaluate the risk of occupational transmission of HIV indicated that health care workers are at minimal risk for HIV transmission from patients with AIDS.

ANA is opposed to mandatory testing because it is not scientifically supported. We agree with Dr. Koop's report on AIDS: "Compulsory blood testing of individuals is not necessary. The procedure could be unmanageable and the cost prohibitive. It can be expected that many who test negatively might actually be positive due to recent exposure to the AIDS virus and give a false sense of security to the individual and his or her sexual partners concerning necessary protective behavior."

The epidemiological benefits of testing do not support the redirection of resources from research and education to test a large body of people who are not high risk. ANA supports the availability of voluntary, anonymous testing with informed consent and appropriate counseling. Individuals seeking services should have access to confidential testing and counseling. Confidentiality of test results must be maintained to prevent discrimination, especially in such areas as insurance, employment and housing. Regardless of whether individuals are found to be seronegative or positive, education programs and individual counseling must be provided.

ANA has endorsed Senate Bill 1575, the Aids Federal Policy Act of 1987, because it establishes a voluntary testing and counseling program for AIDS, assures the confidentiality of such test results, and prohibits discrimination against seropositive individuals.

ANA has historically advocated equitable and humanistic health care for all people. This bill ensures that those people who are tested or treated for AIDS will also have those same rights.

We are pleased that Section 2317(b) requires that seronegative individuals receive information regarding prevention of exposure to and transmission of HIV. The public must understand the limitations of testing for AIDS. Testing does not prevent the disease. People must be instructed to refrain from high risk behavior, and we agree that appropriate prophylactic measures must be practiced by those who are sexually active.

We support Sections 2318 and 2319 which facilitate anonymous testing and prohibits conditional testing for receipt of health services. Individuals must not be anxious regarding disclosure of identity or loss of health care services.

We support the provision on disclosure in Section 2332(e) without consent. A need-to-know test is applicable to the administration of patient care duties. ANA believes the provision of health care is most effective when information pertinent to a patient's treatment and welfare is judiciously disclosed to those directly concerned with that patient's care. Such information facilitates the provision of quality health services while assuring the occupational health of the providers.

Mr. Chairman, we must encourage voluntary, not compulsory, testing with appropriate counseling for high risk behavior groups and not for the entire population. It must be confidential so that people do not have to face both fear of AIDS and the fear of discrimination. Federal policy must not create a disincentive for care.

ANA pledges to continue its role in promoting AIDS prevention and education. We hope that these hearings will result in a logical, scientifically based national health policy on AIDS.

[The prepared statement of Ms. Foley follows:]

AMERICAN NURSES' ASSOCIATION
WASHINGTON, D.C.

TESTIMONY

of the

AMERICAN NURSES' ASSOCIATION

on

ACQUIRED IMMUNE DEFICIENCY SYNDROME

before the

SENATE COMMITTEE ON LABOR AND

HUMAN RESOURCES

Presented by

MARY E. FOLEY, B.S.N., R.N.

CHAIRPERSON

CABINET ON ECONOMIC AND GENERAL WELFARE

SEPTEMBER 11, 1987

1101 14th STREET, N.W. SUITE 200 WASHINGTON, D.C. 20005 202 789-1800

Mr. Chairman, I am Mary Foley, R.N., Chairman of the American Nurses' Association's Cabinet on Economic and General Welfare. I am employed as a Registered Nurse at St. Francis Memorial Hospital in San Francisco. I would like to thank you on behalf of the 188,000 members of the American Nurses' Association (ANA) and its 53 constituent state nurses' associations for this opportunity to address the issue of Acquired Immune Deficiency Syndrome (AIDS). ANA would also like to thank the Chairman and the committee members for their commitment to health care for the nation and their interest and promotion of nursing.

ANA recognizes that the AIDS epidemic has produced fear both nationally and internationally. That fear has initiated emotional and sometimes irrational responses by the public as well as by some legislators and government officials both at the state and federal level. We are here today because ANA believes it is our responsibility as health care professionals to advise the Congress regarding what we consider are the important issues regarding AIDS. It is absolutely necessary that the health care community remain scientific, calm and logical in their approach to the prevention, management and care of the disease AIDS. We are concerned that the actions of well intended [illegible] and respected individuals in government as well as the media will fan the flames of the public's fear and increase it to potentially dangerous hysteria, discrimination and efforts to blame any group or individual for this devastating disease. AIDS is an equal opportunity disease. It affects all races, sexes and ages and with the same result. We are also distressed that some individuals have attempted to discount the existing scientific findings and recommendations made by [illegible] public health scientists and officials.

AIDS is a public health issue not a moral one. [illegible] the devastation of this disease daily while giving nursing care to AIDS patients and providing emotional and bereavement support to their families and friends.

BACKGROUND

Over the past three years, ANA has issued a number of policy statements on the various aspects of AIDS. The Cabinets on Economic and General Welfare and Human Rights have provided substantial leadership on the AIDS issue during this time. Association positions have generally incorporated and supported guidelines issued by the Centers for Disease Control (CDC) regarding infection with Human Immunodeficiency Virus (HIV). In essence, the ANA: 1) believes that the most effective tools for preventing the transmission of AIDS are education and preventive health techniques; 2) opposes discrimination against persons with AIDS or a positive HIV; 3) supports the availability of quality health care, the confidentiality of that care, and respect for the individual affected; and 4) supports increased funding for research and educational efforts.

As the professional organization for registered nurses, ANA has incorporated the concepts of epidemiology and public health in its programs and activities. Community health nursing practice promotes the public's health. The programs, services, and institutions involved in public health emphasize promotion and maintenance of the population's health and the prevention and control of disease. Public health activities change with advancing technology and social values, but the goals remain the same: to reduce the amount of disease, premature death, discomfort and disability. It is within this framework that ANA views AIDS.

The history of public health efforts reveals that infection control, education, and health promotion are central to prevention of infectious diseases. Public health experts believe that educational programs are the key to controlling the epidemic.

AIDS. The [illegible] of transmission through intimate sexual contact [illegible] is now [illegible] [illegible] in the overwhelming majority of cases. The transmission of the disease can be effectively prevented by [illegible] [illegible] [illegible] have well documented [illegible] [illegible] behaviors and [illegible]. These [illegible] [illegible] [illegible] [illegible] [illegible] [illegible] [illegible] counseling directed at changing high risk behaviors have been effective in combatting the transmission of AIDS. Therefore, educational efforts directed toward changing behavior continue to be crucial.

With the documentation of isolated cases of transmission through accidental exposure to infected blood products, the policy debate about mandatory or routine testing has intensified. Some have proposed routine testing of hospital patients. This would occur when HIV screening is automatically incorporated into certain standard sets of laboratory work, although a patient could then request that the test not be done. Mandatory testing would occur when receipt of services is contingent upon submitting to testing, e.g., marriage licenses and immigrants seeking temporary or permanent status. Mandatory testing could also result from federal legislation which would make receipt of federal funds for states, agencies, institutions, and certain other services contingent upon compliance with testing requirements by these bodies, e.g., prisons, hospitals, drug rehabilitation centers, and sexually transmitted disease and family planning clinics.

ASA has addressed the health care aspects of AIDS since [illegible], when the Department of Health and Human Services announced AIDS was the "number one health priority." At that time, ASA stated that all people who have AIDS have a right to equitable and humanistic health care, including: (1) quality treatment, including nursing and social support services; (2) non-discriminatory use of correct isolation procedures; (3) full explanations of required procedures treatments and risks involved; (3) informed choice of treatment/research modalities; (4) confidentiality of the medical record; and (5) respect for privacy and significant relationships.

## IMPACT ON HEALTH CARE WORKERS

ANA is also committed to safeguarding the occupational safety and health of nurses, particularly with respect to exposures to toxic substances and blood-borne diseases. ANA's House of Delegates has stated that:

> "Nurses for decades, have dedicated their careers to promoting the health and welfare of their own clients to the extent that consideration of the nurses' health and welfare has been neglected; nurses are among health care workers in hospitals who routinely face exposure to toxic chemicals, gases, infectious disease . . . and nurses are among health care workers in the community who face exposure to physical harm from infectious disease...
>
> (Resolved) That the American Nurses' Association assist nurses to identify and to report health hazards to appropriate government, health, and nursing agencies or associations; and . . . that ANA continue to encourage research and investigative activities into occupational risks and health hazards encountered by nurses in the workplace."

As we all know, presently there is no cure for AIDS. It is a disease that is nursing intensive. Throughout the course of the disease, it is nurses who provide continuous nursing care during the hospitalization, in the home, and during the hospice phases of this fatal disease. Accordingly, nurses are exposed daily to HIV. However, there is no data to demonstrate that patient-nurse contact is responsible for transmission of the disease AIDS. Data indicates that less than ten health care workers have seroconverted after needle sticks or contact with HIV infected blood or body fluids, although several thousand such incidents have occurred. Since its recognition in 1981, transmission of AIDS has been researched to determine its communicability. The virus has been isolated in the blood, semen, breast milk, vaginal secretions, and cerebrospinal fluid of infected patients. Although the disease is primarily transmitted through intimate sexual contact with infected individuals, the sharing of IV drug use paraphernalia, and perinatal exposure of babies born to infected mothers. It is also spread by contact with contaminated blood and body fluids.

The transmission of HIV is similar to that of the hepatitis B virus. Ironically, many AIDS patients are also infected with hepatitis and cytomegalovirus (CMV). The provision of health care necessitates that nurses and other health care workers have frequent and often intensive exposure to potentially contaminated blood and body fluids. Additionally, those who are responsible for the care of linens, bedclothes and waste disposal may also be exposed to the virus. Linens are contaminated with body fluids and hospital trash contains contaminated waste materials and needles and sharp objects.

Such occurrences increase the potential for health care workers to be exposed to the virus. Since AIDS is similar to Hepatitis, emergency room, operating room, recovery room and critical care nurses are to be considered high risk employees. Studies have shown that AIDS patients require almost double the amount of nursing time as equally ill patients who do not have AIDS. It would, therefore, appear that nurses bear a disproportionate amount of risk of blood-borne diseases including AIDS for which no vaccine is yet available.

However, a study to evaluate the risk of occupational transmission of HIV, hepatitis B, and cytomegalovirus to health care workers with intensive exposure to HIV infected patients reached several conclusions. The Journal of Infectious Diseases reports that:

> "This prospective cohort study was designed to evaluate the risks of occupational transmission of human immunodeficiency virus (HIV), hepatitis B virus (HBV), and cytomegalovirus (CMV) to health care workers with intensive exposure to AIDS-infected patients. [illegible]

> of increased risk of acquiring CMV or HBV was obtained. These results indicate that health care workers are at minimal risk for HIV, CMV, and HBV transmission from occupational exposure to patients with AIDS or ARC, even when intensively exposed for prolonged periods of time.[1]

Accordingly, ANA stands in opposition to mandatory testing of health care workers because it is not scientifically supported. We are also concerned about the possible misuse of such confidential information on employee records and possible adverse insurance and employment actions. Voluntary testing has been effective to date. We believe testing policies must provide anonymity and pre and post-testing counseling. ANA is also utilizing CDC guidelines and the ANA Code for Nurses in promoting written protocols for workplace policies focusing on all infectious diseases.

In its efforts to educate the nursing profession about AIDS, ANA has supplied nurses with over 6,000 copies of the Surgeon General's report on AIDS. We are also collaborating with the American Red Cross to educate health care professionals and the community about the disease prevention and health promotion actions which people can use to prevent the spread of AIDS. ANA distributed over 2,000 copies of the American Red Cross' educational booklet on AIDS. Our constituent state nurses associations including California, Oregon, New York, and Pennsylvania are conducting educational programs for health care professionals and the community on AIDS, its transmission and prevention.

ANA has recognized that education about the epidemiological aspects of the disease is not enough. We have promoted the education and training of health care workers in protective work practices to assure the occupational health of nurses while providing care to AIDS patients. The Association participated in the 1985 revision of CDC's Recommendations for Preventing Transmission of Infection with HTLV-III Virus in the Workplace and recently participated in discussions regarding their clarification and expansion. ANA has continuously urged that nurses and all health care workers study and use the recommendations to assure the safety of health care workers and the welfare of the public.

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[1] Gerberding, J. Louise, Bryant-LeBlanc, Charyl E., Nelson, Kathleen, Moss, Andrew R., Osmond, Dennis, Chambers, Henry F., Carlson, James R., Drew, W. Lawrence, Levy, Jay A., and Sande, Merle A. "Risk of Transmitting the Human Immunodeficiency Virus, Cytomegalovirus, and Hepatitis B Virus to Health Care Workers Exposed to Patients with AIDS and AIDS-Related Conditions." The Journal of Infectious Disease, 1987. Vol. 106: 1-26.

ANA and its state nurses' associations have promoted the CDC recommendations in professional seminars and educational meetings. We have urged the Occupational Safety and Health Administration (OSHA) to issue an Emergency Temporary Standard (ETS) for the hazards of AIDS and other blood borne diseases such as Hepatitis. Since 1984, we have repeatedly urged the National Institute of Occupational Safety and Health (NIOSH) to release guidelines it developed after a task force study on occupational hazards of workers in health care. The ANA review of the draft guidelines demonstrates that occupational safety and health programs in hospitals are non-existent or embryonic at best. Among the hazards addressed in that NIOSH document are specific recommendations on employee exposures to AIDS. We believe these actions are necessary because studies indicate that there is only 50% compliance with the recognized infection control procedures established by CDC.

The recent Mortality and Morbidity Weekly Reports (MMWR) by CDC have revealed that three health care workers, including a nurse, had seroconverted after exposures to blood and body fluids of patients subsequently revealed to be sero-positive for AIDS. The reports also demonstrate that increased education and training of health care workers regarding the CDC recommendations for care of AIDS patients is needed. ANA has reaffirmed its support of the CDC guidelines for preventing transmission of AIDS in the workplace. However, we believe OSHA efforts in enforcement are needed to assure employer/employee compliance.

Employees must be monitored to ensure compliance. In addition to mechanisms that workers are sometimes careless about matters affecting their personal safety. That is not an indictment but an indication that occupational safety and health involves a partnership between employer and employee. However, the employer controls the workplace environment and, therefore, has a greater burden. Accordingly, the employer must enforce the health and safety program, and must be consistent and equitable in order to establish good faith in the program.

Most importantly, medical monitoring and surveillance are necessary to ensure any health and safety program's effectiveness and to protect the workers' health and economic future. Such follow-up is necessary to notify workers in order to enable them to receive appropriate care and in the determination of employer liability when an occupational exposure has occurred. It is especially important that those in charge of AIDS occupational health and safety programs be knowledgeable. In addition, the importance of counseling must be incorporated into any medical surveillance program.

We strongly believe that an OSHA standard would guarantee effective education and training of hospital employees about the disease, its transmission, and the protective measures necessary to reduce occupational exposure. It would also ensure consistency in the implementation of protective health measures. For example, we know of one hospital that requires laboratory personnel to wash their hands while still wearing latex gloves so the gloves can be used repeatedly. An OSHA standard would rectify such practices unless the employer demonstrated their efficacy. Some hospitals do not want to implement universal [illegible] fluid precautions. Instead, they selectively identify [illegible] without [illegible] as well as those [illegible] and [illegible]. These institutions are [illegible] concerned with [illegible]. [illegible] the [illegible] of [illegible] [illegible] not alone in our belief that educational and training programs are necessary. As a major insurer of a California hospital has asked that it demonstrate the existence of education and training of personnel.

Dr. Margretta Styles, ANA President, responded to CDC's report regarding three health care workers who seroconverted after exposures to blood and body fluids with the following statement: "These three cases provide dramatic evidence of the need for registered nurses and all health care workers to continue to be vigilant in their compliance with the guidelines established by CDC. Registered nurses have been in the forefront of providing quality care to victims of AIDS. It is critical that we maintain this commitment while adhering to necessary precautionary measures to protect ourselves and the public we serve."

The cases in question illustrate the need for nurses to demonstrate by example the necessity of observing professionally established infection control precautions. "These three cases do not signal the need for a change in procedures," Styles added. "They instead signal a need to reemphasize vigilance with established procedures. Nursing has a tradition of providing quality care to the victims of once fatal infectious diseases such as poliomyelitis, yellow fever and tuberculosis. This tradition of caring has always meant adhering to proper control procedures to curb the spread of disease. We urge the nursing profession to take a leadership role in continuing to provide safe and effective care to victims with AIDS."

These revelations of worker exposures to AIDS and subsequent seroconversion have resulted in an increased call for mandatory testing for AIDS of specific groups by some legislators and most recently the President. ANA continues to oppose mandatory testing as we believe aggressive disease prevention education for health care workers and the public about the cause, transmission, treatment, care and prevention are the most effective tools to prevent the spread of the disease. We have repeatedly expressed our support of the Surgeon General's recommendations regarding prevention, health promotion and public education.

In November 1988, ANA issued a statement on serologic testing of health care workers in response to legislative inquiries regarding employee health and safety. It stated:

> "Acquired Immune Deficiency Syndrome (AIDS) has been declared the number one health priority by the U.S. Public Health Service. As the public becomes more concerned about the disease, the pressure for routine screening for the Human Immunodeficiency Virus (HIV) antibody is likely to mount. Pressure is apt to focus on health care workers because of their unique role in caring for persons with AIDS, even though the Centers for Disease Control (CDC) does not recommend routine serologic screening for health care workers, regardless of routine participation in invasive procedures.
>
> The American Nurses' Association (ANA) opposes the routine serologic screening of health care workers for the HIV antibody. The HIV virus is transmitted through intimate sexual or blood contact. Therefore, the risk of HIV is transmitted only through intimate sexual or blood to blood contact. Routine serologic screening of health care workers for the HIV antibody will not improve patient care or provide additional protection against HIV transmission in the health care settings. Since the mere presence of HIV antibody in the absence of immunosuppression or symptomatology of Aids Related Complex (ARC) or AIDS does not affect or predict job performance problems or risk to patients, other employees or the affected employee, the employer has no need for such information. Additionally, since the mere presence of HIV antibody does not predict the eventual development of ARC or AIDS, it cannot be used accurately to predict insurance claims or increased costs for employee benefit plans.
>
> ANA does support employer testing if it is done in accordance with the medical surveillance routine recommended by the CDC to document the job exposure to HIV after an occupational accident. Serologic testing after on the job exposure to HIV may be crucial in establishing a workers compensation claim. Personnel policies should be developed for on the job exposure to HIV and address employer payment for initial serologic testing and follow-up tests, record-keeping and access to records, confidentiality, and medical and health counseling during medical surveillance. Health care workers must be encouraged to report occupational accidents and seek appropriate medical surveillance. They must also be assured that such actions will not be subject to retaliatory actions or that the information will not be used in impermissible ways."

ANA's commitment to the occupational health of the nation's nurses [illegible] to the issue of non-discrimination in employment for handicapped individuals. ANA supports the inclusion of infectious disease under the Rehabilitation Act of 1973. ANA filed an amicus brief with the U.S. Supreme Court on September [illegible] 1986, in the case of School Board of Nassau County, Florida v. Gene H. Arline, involving a teacher who was fired after contracting tuberculosis. The Supreme Court held that people with contagious diseases are covered by the federal law which prohibits discrimination against handicapped persons in federally funded programs. ANA agreed with Justice Brennan, who noted that, "Congress acknowledged the society's accumulated myths and fears about disability and disease are as handicapping as are the physical limitations that flow from actual impairment." ANA is in disagreement with the Justice Department's legal opinion that an employer could dismiss an employee who has AIDS if the dismissal were prompted by fear of contagion. ANA will continue to monitor the ethical, legal, and labor relations issues regarding AIDS, and will encourage employer-employee developed policies for catastrophic illness that are compassionate and equitable to prevent discrimination and economic upheaval.

TESTING OF HOSPITAL PATIENTS

On April 1, the President declared AIDS Public Health Enemy Number 1, and called for mandatory testing of certain groups at the state and federal levels. Among those recommended to be tested for the HIV virus were hospital patients. The President's statement also included an admonishment that those with AIDS not suffer discrimination: "This calls for compassion, not blame. And it calls for understanding, not ignorance. ... Let's care for them with dignity and kindness." However, he did not call for legislation or state action to protect against such discrimination.

Although ANA agrees with the President's admonishment that those with AIDS not suffer discrimination, we differ with his recommendations on testing of hospital patients. ADA agrees with Dr. Koop's statement in his report on AIDS: "Compulsory blood testing of individuals is not necessary. The procedure could be unmanageable and the cost prohibitive. It can be expected that many who test negatively might actually be positive due to recent exposure to the AIDS virus and give a false sense of security to the individual and his/her sexual partners concerning necessary protective behavior."

Public health officials almost universally oppose mandatory testing. The epidemiological benefits of testing do not support the redirection of resources from research and education to test a large body of people who are not high risk. The majority of hospital admissions fall out of the demographic parameters that predict disease prevalence. Mandatory testing raises several concerns: first, costs for hospital patients alone have been estimated above $100 million; second, the feasibility of providing the recommended counseling; third, the issues regarding positive prenatal test results affecting birthing decisions; and lastly, the paramount concern for confidentiality of test results. The latter issue raises particular concerns about discrimination in the areas of insurance, housing, and employment.

Mandatory testing of all hospital patients would therefore not be cost effective. Many public health officials also say AIDS testing for hospital patients would be expensive and ineffective. Most health professionals think education is the best way to combat AIDS and protect health care workers. We have to break this cycle of fear. Nurses, doctors, and other health professionals must walk a fine line between unreasonable precautions and those needed to prevent AIDS exposure.

ADA agrees with the American Medical Association's (AMA) recent statement: "Public health authorities have advanced a plausible rationale for their opposition to mandatory testing" for certain groups. "Until these premises are shown to be incorrect, a policy rejected by the vast majority of public health officials, including the Centers for Disease Control and the Surgeon General, cannot be recommended."

Approximately 33.9 million patients received hospital in community hospitals care in 1986. Accordingly, the result of testing all patients is that a multitude of documentation would be maintained. Maintaining the confidentiality of such records would be costly and a technological challenge.

ANA also believes that the potential for misapplication of such testing could affect the provision of health care to patients, if hospitals had to juggle their resources because of misinformed budget cutters.

ANA supports the availability of voluntary, anonymous testing with informed consent and appropriate counseling. Individuals seeking services at drug rehabilitation, sexually transmitted disease, and family planning clinics should have access to confidential testing and counseling about health practices. Confidentiality of test results must be maintained to prevent discrimination, especially in such areas as insurance, employment, and housing. Regardless of whether individuals are found to be seronegative or positive, targeted health education programs and individual health counseling which addresses preventive health practices and the avoidance of high risk behaviors must be provided by qualified health professionals.

AIDS FEDERAL POLICY ACT OF 1987

ANA endorses S. 1575, the AIDS Federal Policy Act of 1987. ANA has historically advocated equitable and humanistic health care for all people. This bill assures that those people who are tested or treated for AIDS will also have those same rights.

ANA, based on public health and humanitarian principles, concern about discrimination, established association policy, and a lack of definitive research demonstrating the efficacy of testing programs, adopted the following at the House of Delegates:

> That the House of Delegates support the availability of voluntary, anonymous HIV testing with informed consent and appropriate counseling by qualified health care professionals and that those seeking services at drug rehabilitation, sexually transmitted disease, and family planning clinics have access to anonymous testing and counseling about health practices.
>
> That the House of Delegates oppose universal mandatory testing for antibodies to the HIV virus.
>
> That ANA continue to urge the federal government to devote substantial funds to support education, research, and treatment in the fight against AIDS.
>
> That ANA reaffirm its commitment to protecting the civil and human rights of persons affected with AIDS as well as those of the caregivers.
>
> That the House of Delegates acknowledge and reaffirm the commitment of the nursing profession to provide care to all people in need of nursing services regardless of the illness or the severity of that illness.
>
> That ANA urge all health care workers to become familiar with and then implement the Centers for Disease Control's Recommendations for Preventing Transmission of HIV Infection in the Workplace.

We believe that S. [illegible] incorporates many of the principles that ANA has endorsed. It establishes a voluntary testing and counseling program for AIDS, assures the confidentiality of test results, and prohibits discrimination against seropositive individuals.

ANA wholeheartedly supports Section [illegible] of the bill which requires documented informed consent to such testing. We would also stress that [illegible] applicants must understand that informed consent must be effective. Individuals who undergo testing and counseling must have the services of personnel with their cultural, linguistic and educational backgrounds in mind. Those same persons are applicable to Section [illegible] of [illegible] and [illegible] the [illegible] counseling. This is especially important because of the potential disproportionate impact of AIDS on the Hispanic, Black and Native American communities. These communities [illegible] health care [illegible] bear the burden of [illegible] testing [illegible]. Additionally, they are [illegible] extremely proud and would be reluctant about [illegible] counseling services designed for middle-class America.

Information about the realities [illegible] confidentiality [illegible] discrimination and public health reporting is important because many of the affected [illegible]. Some who are immigrants [illegible] of their own government [illegible].

We are especially pleased that section [illegible] requires that [illegible] individuals receive information regarding prevention of [illegible] and transmission of HIV. [illegible]

[illegible]

[illegible]

confidentiality laws are stringent, demonstrate that the government must be adamant about its intent to protect the individual's privacy regarding AIDS related health care services.

We believe that the language in Section 2311([illegible]) which refers to a person who knowingly violates the disclosure provision does not refer to inadvertent or accidental disclosure. The term "knowingly" indicates to us that a person must intend to disclose the information. We recognize that some are concerned about the potential for negligent disclosure, and suggest that the committee consider clarification of the language if negligence is to be covered by this section.

We have similar concerns for the section on consent to disclosure as we do for consent to testing. We support the provisions on disclosure in Section 2311(e) without consent as they appear to conform to a "need to know" test applicable to the administration of public health and patient care duties. ANA believes the provision of health care is most effective when information pertinent to a patient's treatment and welfare is judiciously disclosed to those directly concerned with that patient's care. Such information facilitates the provision of quality health services while ensuring the occupational health of the providers. We are also pleased to see that our recommendations to the Chairman regarding the confidentiality of court proceedings and records have been implemented.

ANA also supports [illegible] to prevent discrimination against [illegible] in employment, housing, [illegible] governmental services. [illegible]

[illegible]

In closing, [illegible]

recently at a House Veterans Affairs Committee hearing, "It is paradoxical that the discovery and identification of this virus -- or perhaps several viruses and the way the immune system is attacked -- has required the most sophisticated medical technology that has been developed by man and yet we can control its spread by using the most basic medical principles and education."

To keep people alive, we must encourage testing, and to encourage testing, we must have voluntary, not compulsory testing. We must have testing for high risk behavior groups and not for the entire population. Federal policy must not create a disincentive for care. We must also have confidential testing so that people do not have to face both fear of AIDS and the fear of discrimination. Moreover, testing without adequate counseling is of little value.

ANA pledges to continue its role in the community and the profession in promoting AIDS prevention and education. We hope that these hearings will result in a logical scientifically based national health policy on AIDS.

The CHAIRMAN. Thank you very much. We will include both your statements in their entirety in the record.

Dr. Bristow, first of all, as I understand, the AMA has filed an amicus brief for the Rays.

Dr. BRISTOW. That is correct.

The CHAIRMAN. Do you think their experience is unique?

Dr. BRISTOW. Unfortunately, I doubt that it is.

The CHAIRMAN. What has happened in other similar cases?

Dr. BRISTOW. Well, I think many such cases have not come to the light of day. I think it has probably been handled much more quietly and surreptitiously.

The CHAIRMAN. Have education and legal remedies contributed to helping resolve some of those cases?

Dr. BRISTOW. We believe that the Arline case, for example, points a way in which we can protect individuals who are simply seropositive. That is one of the reasons why we encourage this legislation to make a specific statement that it is not in any way interfering with possible application of the Rehabilitation Act, Section 504.

The CHAIRMAN. What is the position of the Association on the best way of preventing AIDS?

Dr. BRISTOW. Through education and counseling of the general population. It is important that the American people learn those ways in which they can effectively protect themselves, and that such will be accomplished through knowledge, not through adopting an ostrich-like posture.

The CHAIRMAN. Do you believe members of your Association currently understand where and when to recommend AIDS testing?

Dr. BRISTOW. There is a need for an educational program that will involve physicians also. Along that line, we have been working industriously, I would say, during the last two years. As recently as last month, we distributed 325,000 monographs on how physicians can appropriately manage AIDS within their practices to physicians across the country.

The CHAIRMAN. Do some of them face a dilemma about whether to recommend testing, given the tragedy that we heard this morning with regard to the Ray family? Are some of them perplexed by the current dilemma expressed by the Ray family, which is probably known to other physicians? Is this perplexing?

Dr. BRISTOW. Yes, it is. The information concerning an individual's HIV status is potentially loaded with danger for that patient. We are aware of instances of discriminatory behavior. We are aware of problems with protecting the confidentiality of that information. Because of those associated problems, it does pose a dilemma for a physician who is considering the recommendation of serologic testing for a patient.

The CHAIRMAN. Do you think we have any hope of stopping the epidemic through education and counseling while experience like those which the Rays have suffered still occur?

Dr. BRISTOW. Well, I think if that type of experience is allowed to repeat itself, it is only going to have the effect of making individuals who do have a reason to be concerned about their HIV status go into an underground posture, into a posture of avoiding finding out information that could be helpful both to them and to those around them.

The CHAIRMAN. Let us talk a little bit about confidentiality. This is obviously an accepted principle in medical practice. Why do you think there is a need to strengthen confidentiality laws when it comes to AIDS?

Dr. BRISTOW. Because of the concern of a discriminatory backlash against the individual who may, in fact, have a positive serology. Because of that potential for a backlash, it is important that the information be protected. It should be available to those within what I call the medical loop who have a reasonable need to know and to those responsible agencies of government who have a role to play in the provision of services for that individual.

Aside from that medical loop, I think the protection of that information is terribly important. Along with that, we must have safeguards against discriminatory behavior; so in the eventuality that that information does leak out, the individual would still be assured that they will be treated fairly and honestly by their surrounding society.

The CHAIRMAN. Do you feel that there are times when breaches of confidentiality are justified? And what are these times?

Dr. BRISTOW. Well, those times will occur when there is a clear, reasonable likelihood of the endangerment of another person's life. Under those circumstances, there has been a long tradition that physicians are obliged to make every reasonable effort to protect that innocent third party.

This has been shown, for example, in cases of individuals who have been mentally ill and who have expressed a desire to harm a third party to their doctor. It is quite clear that the physician does have a responsibility to see to it that an appropriate warning has been conveyed.

The CHAIRMAN. Of course, you are facing the dilemma that making information available to those at risk increases the risk of the population having that information and that increases the real potential for discriminatory behavior, doesn't it?

Dr. BRISTOW. Yes. Unless it is handled with confidentiality, that is true.

The CHAIRMAN. Do you not think this is giving a special protection to AIDS-infected individuals that we do not give to other individuals who are ill? Is that not giving this whole disease what might be considered a leg up in terms of protections against discrimination?

Dr. BRISTOW. If it is, Senator, it would be my opinion that such increased protection is in the public's best interest because it can assure, at least reasonably encourage, the corporation of those individuals who are in high risk categories as far as their behavior is concerned to come forward and participate in a reasoned and rational approach towards the greater public health needs.

If we do not have that cooperation, it is going to be virtually impossible to contain the infection.

The CHAIRMAN. Now, do you believe that the private sector should adhere to the principles of anti-discrimination? We have had a long history of providing anti-discriminatory protection against minorities, women, elderly, handicapped, etc. in the rehabilitation act and civil rights legislation. Now, we are talking about anti-discriminatory provisions extending to the private sector. You are urging us to do that, as I understand.

What is the reasoning behind your position?

Dr. BRISTOW. Well, our belief is that as long as there are instances of overt discriminatory behavior this will serve as a deterrent to the cooperation of individuals that society needs to have cooperating in the general approach to this illness. Specifically, as far as the Ray case, I think it is an excellent example that we heard of this morning. If that type of activity continues to occur, it is going to discourage parents from trying to do those things which are in the public's best interest.

The CHAIRMAN. Let me go to Mary Foley. Your membership has the closest contact with people who have AIDS, probably with the exception of their families, of course. Your members must have some anxiety about infection.

How do they go on with their duties? What are the real risks to them?

Ms. FOLEY. Nurses have direct care for the patients and have expressed concern about their own safety. But because we are educated in a scientific background, we have found that education of the nursing population has been our greatest asset in alleviating the fears. Nurses who understand the modes of transmission and have been made aware of the CDC guidelines have become extremely comfortable in the direct care of the patients.

We agree that education is the key here. I work on a daily basis with nurses and patients, and I am constantly in an educational process of letting people know what are the real risks. Many state nurses' associations have taken on very aggressive educational and training programs for nurses and other health care workers. Nurses may have the most direct care, but we also have a great deal of knowledge.

I find some of what is sad is the dietary workers, the housekeepers, the other ancillary personnel who often have direct contact are very, very fearful, and have a lack of information. So our membership is becoming more knowledgeable and, therefore, more comfortable.

The CHAIRMAN. There are already well-established principles of confidentiality in the practice of medicine. Nurses are often taken into the confidence of those they care for. Do you think our current standard of confidentiality is adequate? If not, why not?

Ms. FOLEY. We are obligated to respect the confidentiality of patients, and ethically if the nurse were to violate that confidentiality, that would be a very serious breach in their standard of practice and in our ethical code. So for our personal practice, we find that confidentiality adequate.

We do support your provisions for confidentiality, and I think the doctor has made a good point that the circle of employment and insurance information can be quite destructive to somebody's personal well-being. What we have found is the fine line between the need to know in regard of a test result. We do not need to know a test result to be protected in the workplace. There are adequate protections through the CDC guidelines. But if a diagnosis is made, then it is helpful as part of the medical loop, as the doctor recommended, that the nurses involved directly in the care of that patient be provided that information so we can provide comprehensive care, but not so that we are protected. So you have come to, I think, a good decision on that issue.

The CHAIRMAN. Is it difficult to maintain confidentiality in the hospital setting?

Ms. FOLEY. To be honest, it is. There is a grapevine. Hospitals, as any place, encounter a number of people having access to information that may be in excess of what needs to be widely distributed. I think there needs to be some attempt by hospitals to work out notification of the involved personnel without putting red stickers on doors or labels on charts that might alert people that are not directly involved in the care, and then do promote some of the information that goes beyond the network that is necessary.

The CHAIRMAN. So that issue should be addressed more comprehensively?

Ms. FOLEY. Yes.

The CHAIRMAN. On the issue of discrimination, your members get to know these people who are ill and their families well. Nurses have witnessed the painful effects of discrimination on the people they have cared for. Can you tell us something about these observations and what you feel is the most important weapon for fighting discrimination?

Ms. FOLEY. Education. The individuals who are ill with AIDS-related illnesses are extremely ill and at a disadvantage just based on their physical ailment; yet they face discrimination from other health workers, perhaps. They may face discrimination from employment and housing, and their life is difficult enough. They should have nothing more to deal with other than their wellness at that point. The examples of discrimination this morning were just horrifying, but they are not exceptional. That is the sad truth.

I think the degree of discrimination justifies extension of AIDS to some private sector protection because the degree is just phenomenal, and it goes into your practice of your religion, your ability to attend a school, to go to a motel, to get your haircut, the examples are just unending—transportation home from a hospital by a transport team, et cetera, et cetera. So the examples, I think, justify the protection of the individual.

The CHAIRMAN. So you think Federal laws can make a difference?

Ms. FOLEY. Yes, I do.

The CHAIRMAN. Well, it is excellent testimony from both of you, precise, knowledgeable, based upon a good deal of experience, and very helpful. You make the case very, very well. It is basically, I think, irrefutable. Not everyone agrees with me completely.

We want to thank you very much. You have been very, very helpful in your testimony.

Dr. BRISTOW. Thank you.

Ms. FOLEY. Thank you.

The CHAIRMAN. Our next panel will be Bonnie Strickland, Professor of Psychology, University of Massachusetts, President of the American Psychological Association. We are delighted to have her here. She has been a source of information and assistance to me professionally in serving as Chairman of the Health Committee. We are very glad to have her back here before our Committee. We are looking forward to her testimony. She has been a good friend as well. We are delighted to have you here.

## STATEMENT OF BONNIE STRICKLAND, PH.D., PROFESSOR OF PSYCHOLOGY, UNIVERSITY OF MASSACHUSETTS, AND PRESIDENT, AMERICAN PSYCHOLOGICAL ASSOCIATION, WASHINGTON, DC

Dr. STRICKLAND. Thank you.

On behalf of the 95,000 members of the American Psychological Association, I am pleased to have the opportunity to present testimony in support of Senate Bill 1575, the AIDS Federal Policy Act of 1987. My name is Bonnie Strickland. I am a professor of psychology at the University of Massachusetts at Amherst and a member of the National Advisory Mental Health Council and President of the APA.

Mr. Chair, your leadership in developing Senate Bill 1575 demonstrates an awareness that AIDS is the most pressing health issue of our time. Without a vaccine or a cure, we as a society must look to preventing transmission of the AIDS virus as the means of reducing the instance of AIDS.

In many ways, AIDS is a disease of behavior, and as such, prevention in this instance means changing behaviors that pose a risk of transmission of the virus. The behavioral scientists, APA members, have a special role to play in addressing this problem.

Recently, APA coordinated a major policy statement on AIDS counseling and testing. This statement was endorsed by 24 major national health and mental health associations, organizations, including the American Psychiatric Association, the American Hospital Association, and the American Nurses' Association.

I would like to briefly elaborate on the principal points raised in our statement, a copy of which I would like to submit for the record.

The CHAIRMAN. It will be printed in its entirety.

Dr. STRICKLAND. Research indicates that behavior change is most effective when the decision to change behavior is voluntary. Tools such as the HIV antibody test may be an appropriate adjunct to a voluntary program of behavior change. Testing in and of itself, however, is of little use, is only as good as the education and counseling that accompany the test.

A comprehensive program of behavior change will include three discreet components: education, pre-test counseling, and post-test counseling. To the extent possible, the counseling and testing process should be anonymous. If anonymity is impossible, then strict guarantees of confidentiality must be assured. Because there is no way to ensure that confidentiality will be maintained, non-discrimination protections must be provided. Both confidentiality and non-discrimination are central components of a positive public health response. Without such protections, the stigmatized populations most at risk for HIV infection will avoid testing programs altogether, therefore defeating the public health goal.

I would like to commend you, Mr. Chair, for developing a bill which so closely parallels the public health and mental health concerns around AIDS. And, indeed, mental health issues in the area of AIDS are acute. To address these issues, the counseling component in such a program must serve a dual purpose.

First, counseling must be designed to help people to move away from high risk behavior. Data have been developed which suggest that in the absence of counseling people who have tested positive will continue to engage in high risk activities. Moreover, we sometimes forget how important post-test counseling is for the HIV negative individual. We must ensure that this group remains uninfected.

In a New York study, 30 percent of a group of HIV negative individuals did not receive counseling, thought that they had successfully fought off the virus, and were not at risk of future exposure. Following counseling, most of these individuals have become aware of their future risk of infection.

Secondly, counseling may help to alleviate some of the more serious psychological consequences of testing. A body of data indicates the adverse social and psychological consequences associated with knowledge of being infected, including depression, break-up of relationships, social isolation, and disabling levels of anxiety. As more testing has been done throughout the country, reports have also begun to surface about HIV testing-related suicides.

From the Health Crisis Network in Miami, Florida, we know of a young man who, upon learning of a positive test result, killed himself. Tragically, an autopsy indicated that the positive test results was incorrect, a result of grave errors in the testing process. If this young man had received counseling, his life might have been spared.

Indeed, over a two-and-a-half month period, the Network hotline has reported seven suicides related to HIV positive test results.

In another instance, a woman who received her positive test result through the mail killed herself within five hours after crisis intervention with the hotline was attempted.

From New York, we have heard the all too often report of a young college age man who experimented with homosexuality. He was tested by a family physician who provided no counseling. When the young man presented himself to the therapist, he was convinced of his imminent death, put his entire life on hold, including plans for law school, and was seriously contemplating suicide. Fortunately, counseling became available, and the client has successfully adjusted to the fact that he is HIV positive.

These stories, which are typical of the dramas occurring across the country, reflect the severity of the individuals' reactions to HIV test results, a result which increasingly suggests a grim prognosis. Clearly, these circumstances call out for the need to pay close attention to the mental health needs of persons tested for the AIDS virus.

In establishing a Federal policy that considers mental health needs, we must also remain aware of the need to protect the confidentiality of the counselor-client relationship. If this relationship is not protected, the quality of the mental health provisions in this bill may be reduced.

As currently drafted, the bill would allow disclosure of test results to a spouse or sexual partner. This exact language of this provision may have some adverse effects. The prudent public policy goal is to ensure that in any case where a recalcitrant client willfully and knowingly threatens to spread the virus to an identified person, the provider should be encouraged to warn that potential victim. The provider should be encouraged to disclose when disclosure is necessary with respect to preventing a clear and imminent danger of transmission. APA is currently developing a comprehensive position statement on this issue and would be pleased to submit this for the Committee's consideration.

Despite these rather minor concerns, we applaud the overall legislation and pledge our efforts to ensure its passage. I thank you for the opportunity to testify, and I would be happy to try to answer any questions.

[The prepared statement of Dr. Strickland follows:]

American
Psychological
Association

TESTIMONY OF

Bonnie R. Strickland, Ph.D., ABPP

Professor of Psychology

Department of Psychology

University of Massachusetts at Amherst

and

President of

The American Psychological Association

on Behalf of

THE AMERICAN PSYCHOLOGICAL ASSOCIATION

before the

UNITED STATES SENATE

Committee on Labor and Human Resources

on the Subject of

S. 1575, AIDS Federal Policy Act of 1987

September 11, 1987

The Honorable Edward M. Kennedy, Chair
428 Dirksen Senate Office Building

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On behalf of the 87,000 members of the American Psychological Association (APA) I am pleased to have the opportunity to present testimony on AIDS legislation currently pending before the U. S. Senate. My name is Dr. Bonnie R. Strickland, Professor of Psychology at the University of Massachusetts at Amherst and a member of the National Advisory Council of the National Institute of Mental Health. I am particularly pleased to testify in strong support for S. 1575, the AIDS Federal Policy Act of 1987, which recognizes the public health value of providing extensive counseling whenever testing for AIDS antibodies is conducted. APA also views the provisions in the Bill that assure the confidentiality of test results and protect from discrimination persons who test positive as key elements in an effective federal AIDS policy.

OVERVIEW

Mr. Chairman, you and your committee are to be commended. Since your decision to the chair the Labor and Human Resources Committee in the 100th Congress, the Senate has begun to make a progressive response to the AIDS epidemic. Although slow to act initially, both the Congress and the Administration now have picked up the pace in funding basic biomedical and behavioral research on AIDS. Issues of service delivery, care for persons with AIDS and protections against discrimination based on infection with the human immunodeficiency virus (HIV), however, still need to be addressed. You, Mr. Chairman, and the members of this committee have taken the bold steps necessary to address many of these issues. APA would like to take this opportunity to commend you for your leadership in this area.

In many ways AIDS is a disease of behavior, placing great demands on the field of psychology to provide answers to the myriad of behavioral questions that have developed. The manifestation of the disease has severe psychological ramifications that demand successful therapeutic interventions to stabilize the mental health of the infected and sick. The neuropsychological complications brought about by infections of the central nervous system with the HIV virus demand increased attention.

Without any immediate prospect for a cure or a vaccine, the only way to stem the tide of infection is through primary prevention. To be effective in the case of AIDS, behavioral scientists must identify mechanisms for promoting sustained behavior change. The design and implementation of public education campaigns and prevention programs must rely heavily on the skills honed by social and behavioral scientists. Similarly, mechanisms for eliminating public prejudice, discrimination and violence born by fear of this disease must employ basic knowledge from social psychology.

APA's involvement in AIDS stems from our membership's goal of responding to this epidemic with sound public health measures--a response that protects the public and ensures the mental health of persons infected with the AIDS virus. APA's members include clinical providers whose patients manifest the whole spectrum of HIV infection, from HIV positivity to AIDS related complex (ARC) to frank AIDS. We also include among our membership AIDS research scientists who are looking for effective means to promote lasting behavior change, examining the impacts of HIV antibody testing, and, analyzing the ramifications of AIDS for all segments of the population. APA members also include educators who are teaching the public about AIDS and safer sex, industrial psychologists who are addressing the issues of AIDS in the workplace, and individuals who are providing services both professionally and on a volunteer basis to the hundreds of local community-based AIDS service provider organizations across the country. Clearly, APA members are involved in addressing this dreaded disease from a variety of perspectives.

As an organization, APA has taken steps to respond to this crisis since the very earliest days of the epidemic. We have been at the forefront of lobbying for AIDS appropriations and have worked to keep mental health providers aware of the unique aspects of this disease. In 1988, our Council of Representatives adopted a broad, sweeping resolution on AIDS which deplores discrimination against those infected, condemns the use of the epidemic as a vehicle for prejudice, opposes the indiscriminate use of the antibody test, and calls for the confidentiality of patient records while recognizing the need for "large-scale identification of AIDS seropositive persons" as a major public health goal. A copy of this resolution is attached. Most recently, APA has established a Task Force on Psychology and AIDS that will examine more closely the behavioral aspects of this disease and direct the psychological response to the epidemic.

## COALITION FOR AIDS PREVENTION AND EDUCATION: A STATEMENT ON TESTING

Since the advent in 1984 of the HIV antibody test, one of APA's major concerns has been the appropriate use of this test. Simply put, it is APA's position that the HIV antibody test may be an appropriate adjunct to counseling in the effort to promote behavior change away from high risk practices that transmit infection. I would like to further explain APA's thoughts on this issue, comment on legislation that you, Mr. Chairman, have introduced recently and then discuss some of the other legislative initiatives under consideration in the Senate.

Earlier this year, the national debate on the use of the HIV antibody test reached a critical point. At a February 1987 conference sponsored by the Centers for Disease Control (CDC), a policy of mandatory HIV-testing received little support from AIDS experts and public health officers from across the country. Routine screening of blood during hospital admission or of people seeking marriage licenses also was rejected because of its high cost and lack of significant public health benefit. At the same time, public health officials voiced support for offering HIV-antibody tests on a voluntary basis to all those who seek family planning assistance, prenatal care, or drug abuse treatment.

The conference participants generally supported education and counseling as part of a national prevention campaign, and agreed that the HIV-antibody test should be an adjunct to education and prevention counseling and not the reverse. It was also clear from the conference that counseling meant different things to different participants.

In an effort to provide public policy makers with the mental health perspective on the design of a viable education and counseling program, APA coordinated the development of a statement outlining principles on which most of the mental health community could agree. This statement was just released to all members of Congress. It has been endorsed by an informal "Coalition for AIDS Prevention and Education" which is comprised of 24 national mental health and related organizations, including: the American Hospital Association, the American Nurses' Association, the American Psychiatric Association, the American Federation of State, County and Municipal Employees, the National Association of Counties, the National Association of Social Workers, the National Association of State Alcohol and Drug Abuse Directors, the National Coalition of Hispanic and Human Services Organizations, the National Council of Community Mental Health Centers and the National Mental Health Association. Clearly, this statement reflects a broad consensus on education and counseling from a wide spectrum of mental health provider groups and other organizations. I ask that a copy of the full text of this statement be included for the record.

As indicated in the statement of the Coalition for AIDS Prevention and Education, APA believes that stopping the transmission of HIV is an urgent public health goal. Such prevention requires behavioral change which can only be accomplished through education and counseling. Education involves providing individuals with information about HIV transmission and risk-reduction. Counseling involves individualized assessment of risky behavior, facilitation of effective decision making concerning appropriate behavior change, and resolution of psychological and social problems raised by this process.

Routine education and counseling should be made available by the federal government to all people who enter family planning, prenatal, sexually transmitted diseases, or drug abuse clinics. Such counseling also should be routinely available at alternative test sites. In some cases, HIV antibody testing will be an appropriate adjunct to counseling as a strategy for facilitating behavior change or as a source of information necessary for effective decision making. If testing is used, the individual must be given the opportunity to work through psychological issues raised by the testing.

Individuals must also be informed about the the legal ramifications of HIV testing with regard to local and state laws on disclosure, confidentiality and non-discrimination. When individuals are tested for HIV antibody, privacy protections must be assured. Enforceable protections against discrimination based on HIV seropositivity in housing, employment, public accomodations and federal service also should be assured. Sufficient funds should be budgeted to provide effective education and counseling; this includes funding for counselor training, outreach, administration, provision of services, laboratory work and evaluation.

S. 1575: AIDS FEDERAL POLICY ACT OF 1987

Many of the principles endorsed by the APA and the Coalition for AIDS Prevention and Education are reflected in S. 1575, the AIDS Federal Policy Act of 1987. APA commends Chairman Kennedy and his staff for their monumental efforts to achieve a bipartisan consensus on this legislation. Part of the reason for its widespread endorsement is the fact that so many health, mental health, disability and public health groups were consulted during the drafting process. While APA has some concerns with some of the specific provisions of this bill, we are dedicated to working toward passage of this legislation in the 100th Congress. The following comments outline our major concerns regarding the counseling, testing, confidentiality and non-discrimination provisions in the bill.

COUNSELING AND TESTING. Section 2 of this legislation establishes a grants program for AIDS counseling and testing. In our statement, APA and the Coalition argue that the components of a model counseling program should include:

I. Education consists of supplying information about means of HIV transmission and methods of reducing risky behavior. It can be accomplished through a variety of channels, including videotape, audiotape, printed matter, group lectures and discussions, and one-to-one interaction between an educator and a client.

II. Pre-test Counseling is necessarily more individualized and includes risk assessment, recommendations for behavior change and informed consent.

1) **Risk Assessment** consists of reviewing the individual's behavior history sufficiently to determine the presence of risk factors (i.e., high-risk behaviors such as unprotected intercourse and the sharing of unsterilized needles).

2) After individualized assessment, the counselor may make **recommendations for specific behavior changes** for reducing that individual's potential risk of future infection or transmitting the virus to others.

3) **Informed Consent**. Following counseling, the individual should be assisted in making a decision about whether or not antibody testing is appropriate. This discussion will depend upon the individual and the decisions that the individual wishes to make, e.g. parenting. Because it is important to determine if the individual fully understands the possible benefits as well as the possible negative psychological and social consequences of knowing her/his antibody status, oral as well as written informed consent should be obtained before the test is conducted.

III. Testing. If a decision is made to seek antibody testing it may be implemented either through confidential or anonymous testing through the clinic or by referral to an alternative test site.

IV. Post-test counseling is also essential. When the client decides to receive the results, he/she will be individually assessed to determine the extent to which the test result's meaning and implications are clear. When the test result is negative, the individual's understanding of how to prevent future infection should be assessed. When the test is positive, the client must understand how to avoid infecting others; the client also should be assisted in planning to manage the potential psychological and social consequences of seropositive status.

V. **Follow-up counseling** is recommended in special cases where the assessment indicates that the individual's commitment to behavior change is unclear or where severe psychological distress is evident. At the follow-up session the counselor should work with the individual to reduce resistance to behavior change, and should assist the individual in working through any psychological reaction to the test result. The counselor should be able to provide the individual with referrals for individual psychotherapy, group psychotherapy, support groups, social services, alcohol/substance abuse recovery services, or medical services.

S. 1575 would provide for each of these components. The legislation is very clear in its concern about the mental health ramifications of an individual learning about his or her HIV positivity. Empirical research demonstrates that adverse social and psychological consequences are associated with knowledge of one's seropositivity, including extreme depression, breakups of relationships, social isolation, disabling levels of anxiety and, in a number of cases, suicide.

Significantly, this legislation also recognizes the importance of counseling the individual who is HIV negative. Such individuals must not assume that they are not infected. Because the test identifies AIDS antibodies and not the presence of the virus itself, individuals may be infected but may not show any infection in the test result. More importantly, non-infected individuals must practice safer sex in the future if they are engaging in sexual activities with multiple partners and must be counseled accordingly.

CONFIDENTIALITY AND NON-DISCRIMINATION

In providing strong protections for the confidentiality of test results in part B, S. 1575 recognizes that AIDS, ARC and HIV-seropositive status are stigmatizing conditions in our society. The problem is compounded by the prevalence of AIDS among groups that already experience considerable intolerance, e.g., gay men and IV drug users. There is considerable suspicion among persons with AIDS or at risk for AIDS that information about their antibody-status will be unfairly used against them by employers, insurance companies, landlords, and others. The validity of these fears is supported by examples of AIDS-related discrimination, prejudice, and violence. Anonymous testing is preferred, therefore, because it protects clients from unwanted disclosure (and is therefore more likely to elicit cooperation from clients with health professionals) while achieving public health goals. S. 1575 recognizes this need and encourages all grantees to offer anonymous counseling.

Some states have begun to require the reporting of the names of HIV positive individuals to state health departments. In the absence of any real therapeutic intervention, the reporting of individuals who are not sick serves little useful value. Anecdotal evidence suggests that this strategy forces people away from testing programs and into states where mandatory reporting is not required. This situation skews whatever data may be available (i.e., rates of antibody prevalence in a specific geographic area). Although it may be useful for epidemiological surveillance to report HIV infections with relevant demographic characteristics, the reporting of a name associated with a test result raises privacy concerns which may interfere with the broader public health goals.

If anonymity is impractical or impossible, S. 1575 assures that testing must be conducted under the most strict guarantees of confidentiality. Under this legislation, strong fines and criminal penalties accompany the authorization of civil cause of action should confidentiality be breached. Such guarantees are necessary in order to ensure cooperation from stigmatized populations.

Finally, in order for counseling and testing to be effective as part of a prevention campaign, prohibitions against discrimination on the basis of HIV antibody status must be established in law. Under this bill, prohibitions are established against discrimination in employment, housing, public accommodations or governmental services based solely on the fact that a person is HIV antibody positive. In the future, we may need to look beyond this bill and develop protections for those who may be perceived to be at risk for HIV infection as well.

As is necessary, the bill includes provisions allowing for disclosure of test results by the counseling/testing agency with the consent of the test subject. Obviously, disclosure must be allowed for the purposes of counseling. If state law requires, disclosure is permitted to state health officials. Courts may obtain identifying information to prevent "a clear and imminent danger" of transmission. The bill contains several other types of disclosure, two of which are of particular concern to APA. First, the bill would allow for disclosure of HIV test results by a physician or professional counselor to the spouse or sexual partner of a tested individual. Second, S. 1575 would also allow for disclosure to health care professionals to prevent occupational exposure.

As currently drafted, the bill would allow disclosure of test results to a spouse or sexual partner by counselor at the counseling and testing site as well as at other sites to which clients are referred. While APA supports the concept of allowing providers the authority to inform third parties that may be endangered by their clients' high risk sexual behaviors, we are concerned that the language in this bill will have some adverse effects.

Because of the model provided by duty to protect statutes in place in a number of states, the proposed spousal notification provision may have the effect of encouraging all mental health providers affiliated with testing programs to divulge HIV serostatus to the spouse and sexual partners of their clients. This kind of large scale disclosure would necessitate informed consent from potential HIV test subjects who would be first notified that their antibody status may be disclosed to sexual partners and spouses. Rather than reducing barriers and increasing the incentives for voluntary testing, such a provision would create disincentives. Quixotically, this strong disincentive is completely inconsistent with the larger public health goal of increased testing.

In cases in which providers have not warned sexual partners, courts may well cite S. 1575 as an indication of Congressional intent that providers should report serostatus, even though the language of the statute is permissive and does not mandate disclosure. Such a situation could serve to discourage persons who are in need of medical services and mental health counseling from obtaining such assistance. Alternatively, health and mental health providers may make a defensive response and refuse to see members of groups most at risk of infection for fear of engaging in an untenable tradeoff between patient confidentiality and liability concerns.

APA believes that this is not the intention of the Committee. The prudent public policy goal is to ensure that in any case where a recalcitrant client willfully and knowingly threatens to spread the virus, the provider should be encouraged to warn potential victims. Such a standard would relieve most providers from a perceived obligation to regularly report serostatus. This would require a more restrictive disclosure standard that would allow for such disclosure, only if a provider determines that "it is necessary with respect to preventing a clear and imminent danger of transmission." Moreover, because of the special difficulties in notification of sexual partners as opposed to the notification of a spouse, it may be appropriate to limit the disclosure to the latter. Finally, it may be useful to restate the ethical standards of APA and other professional mental health organizations that would require the provider to work with the client to self report serostatus.

The provision dealing with occupational exposure for health care workers reflects the argument that disclosure of serostatus for hospitalized individuals is necessary for the protection of health care workers. Disclosure for the medical benefit of a patient is unquestionably useful. Such medically indicated disclosure would prevent unnecessary release of information, thereby continuing to ensure the patient's confidentiality while also assuring the best level of care. To disclose more broadly will only invite discrimination from poorly informed hospital employees who unduly fear contagion. Incidents abound in which AIDS patients have been completely neglected because some staff are afraid of contagion. We must not promote a federal policy which might serve to encourage such a response.

Thus, disclosure when not medically indicated may be unwarranted and may represent an unwarranted breach of confidentiality. Standard precautions for infectious diseases should be adopted by all health care workers that come into contact with body fluids. By labeling some patients as infectious and thereby hazardous to the health of the hospital worker, an unreal sense of security from other occupational/infectious disease risks is created. Given the infrequency of reported cases of HIV transmission in health care settings in the course of delivering health care services, the risk of contracting AIDS is very minimal. Greater occupational risks are posed to health care workers from hepatitus B, a disease for which there is no widespread antibody testing despite the fact that 300 health care workers die a year from such exposure.

OTHER AIDS LEGISLATION

The following comments address a series of bills which have been introduced in the Senate by Senator Helms. Among other issues, these bills address mandatory testing for AIDS antibodies and mandatory reporting of HIV test results. Taken together these measures reflect an inappropriate and, indeed, harmful response to the AIDS epidemic and would likely result in the wasteful expenditure of limited resources for combatting AIDS.

The major goal of public health programs concerning AIDS is to prevent the transmission of HIV to others. This requires that individuals refrain from engaging in behaviors likely to transmit HIV. The ultimate goal of education and counseling programs, therefore, is behavior change, *not* requiring or encouraging a person to take an HIV antibody test. In order to obtain compliance, psychological studies show that an individual must voluntarily choose to engage in a behavior change program. Otherwise it is highly unlikely that the individual will adopt the behavior change.

Moreover, the value of testing without counseling is highly questionable. Relevant data has recently been collected from individuals who were screened out from enlistment with the military due to their HIV positive status. Interpretation of a positive test result and counseling are not provided to individuals who have been tested through the military recruitment process. The individuals contacted through this survey continued to engage in high risk activities. In the absence of effective and nontoxic antiviral therapies, knowledge of HIV-antibody status may not always be desirable for the individual.

Collectively these bills ignore the track record in existing testing programs. Voluntary testing programs appear to be working. Large numbers of people have already availed themselves of voluntary testing. At the alternative test sites conservative estimates suggest that well over a quarter of a million persons were tested between 1985 and 1986. This does not include the number of persons tested in other governmentally-sponsored test sites or through private providers. A recent survey of testing sites around the country revealed waiting lists for testing at the alternate test sites ranging from one week to two months.

A number of arguments can be made against the mandatory reporting of HIV test results. Often, the model of reportability for sexually transmitted diseases is cited as a reason for requiring HIV reporting. With other sexually transmitted diseases, however, cures exist. With AIDS there is no cure. Arguments have been made about the need to determine the extent of the AIDS infection in the population. Reporting of test results will not provide such information because it will only reflect a selected sample. Moreover, as people are discouraged from testing because of reportability, the sample will certainly be skewed. Other mechanisms for obtaining such information would include a blind seroprevalence study based on sound statistical sampling techniques. It is our understanding that CDC already has such a study underway.

The legislation introduced by Senator Helms does not provide any funding to the states or any federal agency to conduct testing programs. Such a scheme will place an undue burden on already strapped state and federal agencies when funds could better be used for AIDS programs with more immediate and certain benefit. Furthermore, mandatory reporting requirements at the federal level would preempt state prerogatives in the design of an appropriate response to the epidemic.

In addition, there are specific problems with certain specific mandatory testing schemes.

Marriage Licensing: Individuals who plan to get married are the least likely individuals to be infected (cultural attributes of this group suggest that this group is less likely to be sexually active with multiple partners, is less likely to include homosexual/bisexual men and is less likely to include IV drug users). Testing in groups with low incidence will result in unacceptably high rates of false positivity. Because of the low rates of infection, testing marriage licensees is a very poor use of limited resources.

Hospitals: Individuals being admitted to hospitals reflect groups (e.g., the young and the old) that are particularly unlikely to be infected. Hence such testing is an inappropriate use of limited resources. Moreover such a policy may well discourage people in high risk groups from getting the services they desperately need because of fear of testing and accompanying discrimination.

Prisons: Behaviors that result in HIV transmission should be penalized not people. There is every reason to expect that individuals infected with HIV were infected before their incarceration rather than during incarceration. It is inappropriate to punish (i.e., through testing, segregation and significant limits on activities) a model prisoner who was infected with HIV before incarceration and allow the IV drug user/rapist to remain unpenalized. The cost of establishing dual facilities to provide separate facilities from the quarantined HIV-positive population is likely to be prohibitive.

Once again, thank you for this opportunity to present APA's views. I will be happy to answer any questions you may have.

The CHAIRMAN. That is very helpful testimony. I have a few areas that I would like to review with you in hope that you will elaborate on your testimony.

Increasingly, we are concerned not so much about high risk groups but about high risk behavior. Does counseling really change behavior?

Dr. STRICKLAND. Well, I certainly think so. First, folks have to be informed, educated, know what the risk behaviors are. We have heard already so much of the poignant testimony about a lack of knowledge and understanding. But when people are educated, when they are motivated to change, yes, they can certainly change behavior. I have no doubt that counseling helps.

The CHAIRMAN. There is a substantial body of evidence that when there is education and a willingness to change, there can be a significant alteration in behavior.

Dr. STRICKLAND. Yes. And I might just re-emphasize again that one involves the clients or the person that one is counseling for voluntary change. It is much more difficult through force or punishment to have people change behavior. You want to have this person be a willing participant in the behavior change.

The CHAIRMAN. In your opinion, do we need more research in that area so that we can improve our impact?

Dr. STRICKLAND. Clearly we need more research. The American Psychological Association, has interest behavior, and human behavior, behavior change, and we do have a wide body of knowledge, especially within social and personality psychology, that people can obviously change behavior.

I am thinking now not just of the high risk behaviors but the discrimination that we heard talked about this morning. We know that we can help to change attitudes, and help to change behavior through education, through intervention, and through counseling.

The CHAIRMAN. What do you recommend that your members say about the dangers of discrimination when they counsel an individual who is infected with the AIDS virus?

Dr. STRICKLAND. Well, I was interested to hear the earlier testimony on the second epidemic, because it is not just the person with AIDS himself or herself, and not just the immediate family but all of us that suffer from the prejudice and the discrimination against AIDS and AIDS victims. You know, we hope as a country that we are beyond some of this, that we are recapturing a kind of compassion and caring for other people but when people get scared, we see it, we see the prejudice and discrimination. So I think much of our task is to help educate people and reduce the fear, the almost phobia, about AIDS.

The CHAIRMAN. And they counsel on this? The counselors provide that kind of help and assistance and counseling?

Dr. STRICKLAND. I might also add we have seen an increase in violence against some of the high risk groups, especially gays and lesbians, and this is prejudice in action, if you like, when people are attacked.

The CHAIRMAN. That is increasing, is it?

Dr. STRICKLAND. Yes, it is. There is clear evidence of that.

The CHAIRMAN. For the record, some have advocated quarantine of those who are tested for the AIDS virus and are found to be infected. Would this not be easier than trying to change behavior?

Dr. STRICKLAND. Well, I cannot imagine we are going to quarantine 1.5 million people in this country that are infected with the AIDS virus. And if you are infected with the AIDS virus, we really do not know altogether what it is going to mean in the future.

As the physician was saying earlier, people who have evidently picked up the AIDS virus through the blood supply seem to be at less risk of developing full blown AIDS than some of the high risk groups. We know, for example, that pediatric AIDS seems to have a different kind of course than adult onset AIDS.

So I think it would be grossly unfair, Fascist, if you like, to begin to quarantine people or to put people away simply because of a blood test.

The CHAIRMAN. Do we have enough counselors?

Dr. STRICKLAND. No. This is an unprecedented health problem. This country has never been faced with something like this before. It is unprecedented in that across time AIDS seems to be so fatal. It is unprecedented in terms of the social phobia around AIDS, the fears around AIDS. It is unprecedented in the numbers of people that it is affecting. It is unprecedented in terms of the kind of prejudice and discrimination that AIDS generates. AIDS is present in groups that have been traditionally discriminated against, and now people have more reason, if you like, or believe they have more reason to discriminate.

So we must make an unprecedented public health effort to meet this dread disorder, and this is going to include considerably more education and counseling.

The CHAIRMAN. How will we know when we have got the right number? Can you estimate what the right number would be?

Dr. STRICKLAND. Well, I do not know that we will know that until all the people who need care have opportunities for assistance.

The CHAIRMAN. Finally, professional psychologists are already expected to practice with adherence to the principle of confidentiality. Do you feel that legislation is really needed to assure that they do?

Dr. STRICKLAND. I am sorry. That the legislation?

The CHAIRMAN. That we need to pass legislation to make sure that we are going to provide adequate protection in the area of confidentiality.

Dr. STRICKLAND. I think so. I think it is of great help to have such.

The CHAIRMAN. Do you think it is needed? Will it be needed now given the whole AIDS phenomenon in our society?

Dr. STRICKLAND. Yes, no question about it.

The CHAIRMAN. Well, that is very helpful. I want to thank you again.

Senator Metzenbaum, do you have any questions?

Senator METZENBAUM. No questions.

The CHAIRMAN. I want to thank you very, very much for your presence here today.

We have the last panel, Kristine Gebbie, who is the Chairman of the AIDS Committee, Association of State and Territorial Health

Officers, McLean, Virginia; and Joan Banach, who is Director of Communications, American Medical Record Association, Chicago, Illinois.

I want to thank Senator Metzenbaum who is willing to chair the hearings for our final two witnesses. I assure them that I will have the opportunity to examine their comments in their entirety from the record. We look forward to hearing from them.

I think maybe Kristine Gebbie, if you would start off.

## STATEMENTS OF KRISTINE GEBBIE, CHAIRMAN, AIDS COMMITTEE, ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICERS, McLEAN, VA; AND JOAN BANACH, DIRECTOR OF COMMUNICATIONS, AMERICAN MEDICAL RECORD ASSOCIATION, CHICAGO, IL

Ms. GEBBIE. Thank you.

Because you have heard so many of these points already today, and because yuou will have an opportunity to read my written statement, I am going to just highlight some key points from the point of view of the Nation's chief health officials of each of the 50 states.

We are the ones responsible for protecting the public health within our jurisdictions and, in the course of attacking this epidemic, have come to clearly see the need for continued attention to both confidentiality and protection against discrimination as essential.

In fact, we have just concluded a major two-day policy session involving many of the parties interested in this epidemic, and we will shortly be publishing a report identifying the principles for protection of confidentiality and prevention of discrimination which we believe are essential around this epidemic. We will include some guidelines which might be included in either State or Federal legislation.

The principles of assuring that testing is available, accompanied by counseling, are clearly covered in the legislation that is being proposed, and are supported by us from the states. With regard to confidentiality, that has already been mentioned as essential because without assurances of confidentiality and non-discrimination, persons most in need of personal counseling and access to voluntary testing will not come forward.

Increased legislation is necessary because not all states have clear-cut confidentiality protections in the statutes, although it is in the professional ethics of most of the practitioners. The lack of legal sanctions which allow us to go back and seek correction is a gap. Doing it on a national basis will provide coverage comprehensively and avoid the lengthy process of catching up in each one of the states.

The statutes must assure that there are absolutely the narrowest possibilities for violating that confidentiality, those provided under reporting by law to state health agencies, and those that might occasionally be involved with notifying third parties; although I would point out you can notify a third party of their potential risk of infection without telling them the name of the source. That has been done in investigation of other communicable diseases for a hundred years.

Discrimination prohibitions, I think, are also essential. I would suggest to you that our report will point out the need to consider discrimination not just of infected people and not just people suspected to be infected, but people who are perceived as being at risk of infection because of their association with some particular behavior or identification. So that may need to be looked at in the language chosen.

The entire process of pulling together this legislation, starting from the general principles which have been covered in the bill already printed, are very important to our members and our association. And I wish to repeat, as I have in my written testimony, our availability to work with staff of the Committee and individual members of the Committee in crafting the final language which will most fully carry out the intent of supporting counseling and testing, assuring confidentiality, and prohibiting discrimination as strongly as we can.

Thank you for the opportunity.

[The prepared statement of Ms. Gebbie follows:]

ASTHO
AIDS Testimony
S. 1575
Senate Labor and Human Resources Committee
Washington, D.C.
September 11, 1987
Kristine Gebbie

It is a pleasure to testify today on behalf of ASTHO, and as the chief public health official of Oregon. The Association of State and Territorial Health Officials strongly supports this bill to provide increased funds for HIV antibody testing/counselling, to assure confidentiality, and to prohibit discrimination. The resource it represents will be of great help in our efforts to combat the epidemic.

AIDS affects all levels of government; federal, state and local health officials have been collaborating to make the best use of our scarce resources. Federal leadership is extremely helpful by setting an example of support and by setting a tone of services. Coordination through other levels is critical, in order to avoid conflicts of policy and to make most efficient use of all resources.

This bill could purchase 7 million counselling and testing sessions a year - a significant increase which needs to be wisely invested. My testimony is organized around the major sections of the bill, in order.

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Counselling and Testing Grants

There is an essential link of counselling and testing. In many cases we see "the test" as the lure to get persons at risk into counselling, which is a critical preventive step. Because counselling and testing programs are already in place, I would suggest that grantees be state government or local agencies working in conjunction with a statewide plan. (Multiple federal grants directly to local agencies could lead to federal bureaucracy increase, as well as the risk of competing test sites or lack of system at the local level.) I believe that basing the grant amount on reported cases of AIDS would be a problem. The CDC report is inaccurate for many states, because of some underreporting, but principally because of migration after diagnosis (Oregon has approximately 100 more cases than the CDC figures would show). More importantly, prevention is essential everywhere and perhaps more timely in lower incidence states. Therefore it would be appropriate to include in a formula something like total population of the state.

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Confidentiality

ASTHO has previously said:

- "RECORDED PATIENT INFORMATION MUST BE KEPT IN STRICTEST CONFIDENCE; any breach of confidence may represent risk to insurability, job security, and other civil liberties.
- Public health systems for ensuring confidentiality of patient identifiers should be carefully reviewed for the adequacy of legal safeguards. When necessary to preserve the public health, the state or local public health agency may confirm information contained in public health case reports or may notify other medical personnel or health officials of the minimum information necessary.
- No public health data that could be used to identify individuals, either directly or indirectly, will be made available to anyone for on-public health purposes. In particular, such data will not be disclosed to the public, to parties involved in civil, criminal, or administrative litigation, or to non-health agencies of the federal, state, or local government. The assurances of non-disclosure should be embodied in statute, confirmed in health agency policy, and supported by regular staff training."

This bill is consistent with those principles, and would provide a national standard of confidentiality.

Informed Consent -

ASTHO has previously said:

"HTLV-III antibody testing should be preceded by individual informed consent and by counselling of the person to be tested." We take this to mean that the provider must document information given to the potential testee, and the agreement of the individual to be tested. Focus on getting a signature on a piece of paper, (written consent) can cause:

- Problem with anonymity, where it is offered
- Problem of routinization, in which the signature becomes more important than the information transmitted or the understanding achieved
- Any consent should include information on required reporting or expected sharing of test results with other providers in direct care setting.
- Federal action on informed consent can save major effort in local law writing or revisions, but should carefully consider wide range of issues before final action.

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### Anonymous/Pseudonym testing -

Bill would require testing be available without personal identifiers. If not prohibited by state, this departure from usual public health practic requires careful consideration. I would prefer that such testing be allowable for funding if it is consistent with local policy based on epidemiologic evidence. In Oregon, for example, each county must offer one anonymous test site. This policy was determined after several months of data gathering in both regular and anonymous circumstances.

### Disclosure to Health Professionals

The requirement of disclosure of test results to other health care workers presumed to be at occupational risk runs counter to the very firm general recommendation of universal precautions against blood born diseases. The disclosure is needed in only very rare circumstances related to care and should be covered in informed consent

### Court Orders -

The best of current state laws provide protection from examination of public health records. This law goes in another direction, by allowing the health department to go to court to seek information from others. This would be helpful in a limited number of cases, and is probably not an essential feature of the bill.

Contact Notification -

This bill sets up any physician or professional counsellor to do contact followup without patient consent. The example generally cited in discussion of this issue is the family practitioner caring for an infected individual and that person's spouse. The physician feels a duty to warn the spouse even if the patient refuses to do so and refuses consent for the physician to do so. This is a difficult area. This approach may be used to avoid reporting, on the rationale that the needed followup has already been done. ASTHO is tending toward requiring reporting to the health department; the provider may then do contact as an agent of the health department, or the health department may do it. I believe this is consistent with the AMA's policy in this area as well.

Discrimination - Prohibition -

This section is an essential support for all other activities. Current statutes are apparently unclear, and a direct federal policy will provide leadership and a standard for action

ASTHO is pleased to assist in work on bill, and in implementation of its provisions in the fight against the AIDS epidemic.

Senator Metzenbaum [presiding]. Thank you very much. Ms. Banach.

Ms. Banach. I am Joan Banach, Director of Communications for the American Medical Record Association. I represent 28,000 members whose primary responsibility is to assure accuracy and confidentiality of patient information.

AMRA members hold management positions in a variety of health care settings. For this reason, we are especially committed to the highest ethical standards in the use of health information. Our interest in confidentiality statutes derives from our position as the primary patient advocate in any of these health care settings. So our interest in adequate laws to protect patients' rights is because of our advocacy position rather than from any personal incentive.

As a verification of AMRA's position, I have made available to this Committee copies of two of AMRA's position statements: the confidentiality of patient health information in general, and the other is one which offers guidelines for the handling of health data on individuals tested or treated for the HIV virus. With your permission, I would ask that these be made a part of my testimony.

Senator Metzenbaum. It will be.

Ms. Banach. AMRA recognizes that any law or statement from whatever source—whether it is Federal or State or local or our own policy statement—is only as effective as the persons who are responsible for assuring that confidentiality protection. In any health care setting and in places where we often have thousands of employees, hundreds at least, it takes only one person to breach confidentiality one time before the patient loses any kind of confidence in that health care institution.

Because there is no real consistency in laws which protect confidentiality across the country, our association strongly supports any legislative effort which would achieve that kind of consistency. There are some states that have laws which may be too strict. I offer, for example, the current California and Colorado laws; and there are other states which afford little or no protection of confidentiality as was true until recently of Montana.

Whether it is federally or state mandated, we believe that there needs to be a greater uniformity in protecting patient confidentiality, and we offer as the best suggestion of this the Uniform Health Care Information Act, which we believe clearly offers good legislative language that could be adopted.

This brings me to the current AIDS Federal Policy Act of 1987, S. 1575. We support this bill very strongly because it opts for voluntary testing and counseling, and it provides important protection for the individuals tested. But we are concerned about the applicability of the legislation in states where inadequate confidentiality laws exist. We would encourage the inclusion of the language of the Uniform Health Care Information Act in this legislation, or at least some minimal standards by the Federal Government. Because whether it is true or not, people say, well, we do have confidentiality laws. That may be true, but the public at the present time perceives that confidentiality is sorely lacking, and we have heard examples of that today. So this issue needs to be addressed again by the Federal Government.

There are precedents for this kind of Federal mandate; for example, the highway laws. The highway funding was controlled by the Federal Government until the laws of the state were changed concerning the drinking age. AMRA would strongly support any type of such financial incentives.

One of the sensitive areas of the Senate 1575 is the whole issue of disclosure and redisclosure of patient information. Our association's position on this is that the physical record itself is the property of the health care provider or the institution, but the information belongs to the patient. Therefore, it is the patient's right to determine who has the right to that information, and the patient who has a right to determine how that information should be released, unless it is otherwise proscribed by law.

In fact, in the statement which I have submitted for the record there are guidelines. We have spelled out in one of the consent forms that we offered as an example the degrees and the persons that ought to be given access to information concerning people affected by the HIV virus.

The Uniform Health Care Information Act has been suggested as an example of good legislation, and someone has argued, well, it does not exactly address AIDS. That may be true, but the language is such that it would afford the right kind of protection for people who are being treated for an AIDS condition.

I will be happy to answer any questions that the Committee may have.

[The prepared statement of Ms. Banach, with attachments, follow:]

AMRA

TESTIMONY

OF

JOAN BANACH, RRA

DIRECTOR OF COMMUNICATIONS

AMERICAN MEDICAL RECORD ASSOCIATION

CHICAGO, ILLINOIS

BEFORE THE COMMITTEE ON LABOR AND HUMAN RESOURCES

UNITED STATES SENATE

SEPTEMBER 11, 1987

AMERICAN MEDICAL RECORD ASSOCIATION
[illegible] N. Michigan Avenue Suite [illegible] Chicago Illinois [illegible]

GOOD MORNING. MR. CHAIRMAN. MY NAME IS JOAN BANACH AND I AM THE DIRECTOR OF COMMUNICATIONS FOR THE AMERICAN MEDICAL RECORD ASSOCIATION. AMRA IS A PROFESSIONAL ASSOCIATION WITH 28,000 MEMBERS ACROSS THE COUNTRY WHO ARE RESPONSIBLE FOR ASSURING THE ACCURACY AND CONFIDENTIALITY OF PATIENT INFORMATION. OUR MEMBERS HOLD MANAGEMENT POSITIONS NOT ONLY IN HOSPITALS BUT ALSO IN NURSING HOMES, AMBULATORY CLINICS, PHYSICIANS' OFFICES AND RELATED HEALTH CARE FACILITIES. SINCE ITS FOUNDING IN 1928, AMRA HAS BEEN COMMITTED TO THE HIGHEST ETHICAL STANDARDS IN THE USE OF HEALTH INFORMATION.

AMRA WELCOMES THIS OPPORTUNITY TO SHARE ITS VIEWS WITH THE COMMITTEE AS IT ATTEMPTS TO ADDRESS A RANGE OF VERY COMPLEX AND CONTROVERSIAL ISSUES. WE CERTAINLY COMMEND THE COMMITTEE AND THE LEADERSHIP OF THE CHAIRMAN FOR YOUR EFFORTS ON THIS SUBJECT, A SUBJECT WHICH IS CHARACTERIZED BY ITS CHALLENGE TO FIND APPROPRIATE ANSWERS TO THE MANY DIFFICULT QUESTIONS IT RAISES.

OF ONE FACT THERE IS NO DOUBT. AIDS IS A HUMAN TRAGEDY OF UNKNOWN PROPORTIONS. AS A NATION WE MUST MOBILIZE OUR EFFORTS TO EDUCATE THE MEDICAL COMMUNITY AND THE GENERAL PUBLIC BY MAKING CLEAR AND ACCURATE INFORMATION ABOUT AIDS AVAILABLE TO EVERYONE. AT THE SAME TIME, I AM HOPEFUL THIS GOAL IS INCORPORATED INTO THE COMMITTEE'S WORK WITH THE CONGRESS.

IN MY TESTIMONY TODAY, I WILL ADDRESS CONFIDENTIALITY AS IT PERTAINS TO AIDS AND OUR PERSPECTIVE ON THIS ISSUE. I WILL ALSO PROVIDE COMMENTS ON S. 1575, THE BILL WHICH SENATOR KENNEDY AND OTHERS INTRODUCED RECENTLY.

AMRA MEMBERS ARE STRONGLY COMMITTED TO PUTTING INTO ACTION THE PRINCIPLES SPELLED OUT IN OUR OWN POSITION STATEMENT, WHICH IS ENTITLED "CONFIDENTIALITY OF PATIENT HEALTH INFORMATION;" THIS WAS FIRST PUBLISHED IN 1978 AND HAS BEEN UPDATED SEVERAL TIMES. I HAVE MADE COPIES AVAILABLE TO THE COMMITTEE AND, IF APPROPRIATE, WOULD ASK THAT THE STATEMENT BE INCLUDED AS AN INTEGRAL PART OF OUR TESTIMONY. AS A SUPPLEMENT TO THAT STATEMENT, AMRA'S BOARD OF DIRECTORS HAS RECENTLY COMPLETED WORK ON A NEW POLICY STATEMENT WHICH SPECIFICALLY ADDRESSES AIDS. CURRENTLY IN THE PRINTING PROCESS, THAT STATEMENT WILL BE AVAILABLE IN APPROXIMATELY TWO WEEKS. HOWEVER, I DO HAVE A COPY OF THE FINAL STATEMENT WITH ME AND WOULD BE GLAD TO SHARE IT WITH THE COMMITTEE IF APPROPRIATE.

FIRST AND FOREMOST, I MUST EMPHASIZE THAT ANY CONFIDENTIALITY LAW THAT IS ADOPTED AT THE LOCAL, STATE, OR FEDERAL LEVEL WILL BE ONLY AS EFFECTIVE AS THOSE WHO ARE RESPONSIBLE FOR IMPLEMENTING IT AND ASSURING PATIENT CONFIDENTIALITY. FOR EXAMPLE, WHEN A PATIENT IS ADMITTED TO A 500 BED HOSPITAL, SCORES OF PEOPLE HAVE ACCESS TO AN INDIVIDUAL'S MEDICAL RECORD IN ORDER TO PERFORM THEIR WORK. IT TAKES ONLY ONE PERSON TO BREECH CONFIDENTIALITY AND, IN EFFECT, DESTROY THE PATIENT'S CONFIDENCE IN THE INSTITUTION AND ITS EMPLOYEES.

SECONDLY, IT IS IMPORTANT TO NOTE THAT THERE IS NO REAL CONSISTENCY TO STATE LAWS PROTECTING CONFIDENTIALITY ACROSS THE COUNTRY. UNTIL RECENTLY, IT WAS OUR PROFESSIONAL OPINION THAT ONLY TWO STATES, CALIFORNIA AND COLORADO, HAD LAWS ADEQUATE TO

PROTECT THE CONFIDENTIALITY OF AIDS PATIENTS. SINCE THAT TIME, I HAVE LEARNED FROM OUR COLLEAGUES IN CALIFORNIA THAT THE LAW THERE IS DIFFICULT TO MANAGE. I ALSO HAVE BEEN ASKED NUMEROUS TIMES HOW THE ASSOCIATION FEELS ABOUT COLORADO'S TRACKING REQUIREMENTS. FOR THOSE OF YOU WHO MAY BE UNFAMILIAR, AS I UNDERSTAND IT, COLORADO LAW REQUIRES TRACKING OF ALL SEXUAL CONTACTS WITH THOSE WHO TEST POSITIVE FOR THE AIDS VIRUS. IF AN INDIVIDUAL DOES NOT HAVE THE RIGHT TO MAKE THOSE CONTACTS HIMSELF FIRST, PRIOR TO GOVERNMENT INTERVENTION, I MUST SERIOUSLY QUESTION THE ADVANTAGES OF SUCH LEGISLATION.

WHAT IS IMPORTANT TO NOTE HOWEVER, IS THE EXISTENCE OF A PIECE OF LEGISLATION WHICH, IN OUR OPINION, IS A MODEL WHICH ALL STATES CAN ADOPT. THE UNIFORM HEALTH-CARE INFORMATION ACT, ADOPTED BY THE NATIONAL CONFERENCE OF COMMISSIONERS ON UNIFORM STATE LAWS IN 1985, ENDORSED BY AMRA IN THAT SAME YEAR, AND APPROVED BY THE AMERICAN BAR ASSOCIATION IN 1986, GOES THE EXTRA MILE TO ADDRESS CONFIDENTIALITY THOROUGHLY AND SUCCINCTLY. HOWEVER, TO DATE, ONLY ONE STATE - MONTANA, HAS ENACTED THIS PIECE OF MODEL LEGISLATION. AMRA STRONGLY SUPPORTS ANY EFFORT, WHETHER IT BE AT THE STATE OR FEDERAL LEVEL, THAT ENCOURAGES ADOPTION OF PRINCIPLES SPELLED OUT IN THE UNIFORM HEALTH CARE INFORMATION ACT. WE HAVE BEEN WORKING WITH SENATOR QUAYLE'S OFFICE ON THIS VERY SUBJECT, AND WE ARE HOPEFUL THAT THE COMMITTEE WILL GIVE HIS POSITION SERIOUS CONSIDERATION.

JUST ONE MORE PREFATORY NOTE BEFORE ADDRESSING S. 1575. AS MEDICAL RECORD PRACTITIONERS WE ARE RESPONSIBLE FOR ASSURING THAT

ACCURATE INFORMATION IS RECORDED AND ACCESSIBILITY TO THAT INFORMATION IS GRANTED ONLY TO THOSE WHO HAVE A LEGITIMATE NEED TO KNOW. TO US, A POSITIVE TEST IS A POSITIVE TEST. THEREFORE, THE DEBATE OVER FALSE POSITIVES AND FALSE NEGATIVES SIMPLY DOES NOT FALL INTO OUR REALM OF RESPONSIBILITY.

WHICH BRINGS US TO S. 1575. AMRA COMMENDS THE CHAIRMAN FOR HIS EFFORTS IN THIS AREA AND WE ENDORSE THIS PIECE OF LEGISLATION. WE BELIEVE IT IS SOUND AND PROVIDES IMPORTANT PROTECTION FOR INDIVIDUALS WHO CHOOSE TO BE TESTED FOR AIDS. IT ALSO PROVIDES THE APPROPRIATE FLEXIBILITY FOR THE REPORTING OF CRITICAL INFORMATION TO APPROPRIATE GOVERNMENT AUTHORITIES.

WE DO, HOWEVER, HAVE SOME SPECIFIC COMMENTS THAT, AS THE COMMITTEE DELIBERATES ACTION ON THIS BILL, WE BELIEVE YOU SHOULD CONSIDER.

SECTION 2315 REQUIRES THE SECRETARY TO PROVIDE GRANT MONEY ONLY TO GRANTEES WHO ARE ABLE TO ENSURE CONFIDENTIALITY IN ACCORDANCE WITH FEDERAL, STATE, AND LOCAL LAWS. IF A STATE HAS INADEQUATE LAWS TO PROTECT CONFIDENTIALITY AND THE GRANTEE OBEYS THE LETTER OF THE STATE LAW, IS THAT STATE ELIGIBLE FOR GRANT MONEY? UNDER THE PROPOSED LANGUAGE, WE PRESUME SO, AND WE FIND IT DIFFICULT TO SUPPORT SUCH BROAD LANGUAGE. ON THE OTHER HAND, AS WE UNDERSTAND IT, THE INTENT OF SECTION 2315 IS TO ASSURE CONFIDENTIALITY. PERHAPS A REQUIREMENT OF MINIMUM STANDARDS, PARALLEL TO THOSE OUTLINED IN THE UNIFORM H[illegible] CARE INFORMATION ACT, COULD BE REQUIRED TO ENCOURAGE STAT[illegible] MEET A CERTAIN LEVEL OF PROTECTION. WE SIMPLY DO NOT BELIEVE THE PREMISE THAT EXISTING STATE

LAWS ARE ADEQUATE TO ASSURE CONFIDENTIALITY. ACCURATE OR NOT, THE PUBLIC PERCEIVES THAT ASSURANCES OF PROTECTION ARE SORELY LACKING.

IN FACT, WE BELIEVE THERE IS PRECEDENT FOR SUCH AN APPROACH. THE CONGRESS HAS REFUSED TO RELEASE STATE HIGHWAY FUNDS UNLESS THEY RAISE THE DRINKING AGE TO 21. THE ASSOCIATION WOULD STRONGLY SUPPORT THIS TYPE OF FINANCIAL INCENTIVE TO STATES TO ENCOURAGE THEM TO ADOPT UNIFORM LAWS TO PROTECT CONFIDENTIALITY.

SECTIONS 2331, 2332, AND 2333 ARE SOUND AND WE SUPPORT THEIR ADOPTION. WHILE ITS LANGUAGE IS DIFFERENT FROM THE UNIFORM HEALTH INFORMATION ACT, WE BELIEVE THE INTENTION IS SIMILAR AND THEREFORE SUPPORT IT.

IN TERMS OF REDISCLOSURE, I WANT TO EMPHASIZE A POINT I MADE EARLIER. WHILE REDISCLOSURE IS CERTAINLY AN ISSUE WORTH DISCUSSING, ANY LEGISLATION ADOPTED, WHETHER IT IS AT THE LOCAL, STATE, OR FEDERAL LEVEL, IS ONLY AS STRONG AND EFFECTIVE AS THOSE WHO MUST ADHERE TO ITS CONSTRAINTS. IF INFORMATION IS INAPPROPRIATELY REDISCLOSED AND SANCTIONS DO NOT OCCUR, THEN THERE IS LITTLE POINT TO LEGISLATION.

ONE LAST COMMENT, AND I WILL BE GLAD TO ANSWER ANY QUESTIONS YOU MIGHT HAVE. THERE ARE NUMEROUS REFERENCES THROUGHOUT THE BILL TO PATIENT "IDENTIFYING INFORMATION." WITHOUT SEEMING REDUNDANT, I WOULD ASK THE COMMITTEE TO CONSIDER A MORE SPECIFIC DEFINITION OF "IDENTIFYING INFORMATION," AND WOULD SUGGEST THE LANGUAGE INCLUDED IN EITHER THE UHIA BILL OR OUR OWN STATEMENT ON

CONFIDENTIALITY.

AGAIN, I WOULD LIKE TO COMMEND THE COMMITTEE FOR ITS EFFORTS IN THIS AREA, AND THANK YOU FOR THE OPPORTUNITY TO TESTIFY HERE TODAY.

I WILL BE GLAD TO ANSWER YOUR QUESTIONS.

# GUIDELINES FOR HANDLING HEALTH DATA ON INDIVIDUALS TESTED OR TREATED FOR THE HIV VIRUS

## INTRODUCTION

Acquired immunodeficiency syndrome (AIDS) has become one of the major public policy issues in the United States. The potential for invasion of privacy and resultant discrimination is one of the most significant components of this issue. The health care community must constantly balance its duty to protect third parties from transmission of the human immunodeficiency virus (HIV) with its duty to protect the privacy of the individual with HIV virus antibodies in the blood.

The American Medical Record Association (AMRA) is committed to the highest ethical standards on the confidentiality and security of individually identifiable health information.

In its position statement "Confidentiality of Patient Health Information," AMRA has provided guidance in the development of policies for the collection, storage, and dissemination of health care information. As the custodian of the health record and secondary information, the health record practitioner increasingly faces a dilemma: fulfilling the obligations for information needed to serve the patient, the institution, and the community, while, at the same time, protecting the patient from unauthorized, inappropriate, or unnecessary intrusion into the highly personal data of the health record.

Through the guidelines which follow, AMRA communicates its concern for the privacy of individuals infected with the HIV virus and individuals testing positive for HIV antibodies. These guidelines address the following topics: HIV testing, data collection, secondary records, storage and security, release of information, employee responsibility, and responsibility to the public. Nothing in these guidelines should be construed to override existing state or federal laws.

Health care facilities may provide the following types of services associated with the detection of antibodies to the HIV virus and the treatment of infected patients:

- screening for the presence of antibodies to the HIV virus
- diagnostic and treatment services for inpatients and outpatients

## SCREENING SERVICES

Health care facilities may choose to offer screening programs to detect the presence of antibodies to the HIV virus. Since such programs may identify individuals who display no signs of infection with the HIV virus, the health care facility should maintain screening records in a confidential manner.

### Testing/Data Collection

Appendix A outlines specific procedures which may be used to conduct a confidential screening program for antibodies to the HIV virus.

### Secondary Records

The only records which should be maintained are a test request form and a laboratory report form containing the test results. No secondary records such as logs or indexes should be maintained on individuals screened for the HIV virus.

### Storage and Security

Screening records should be maintained in secure manual files for the length of time required by law. Consideration should be given to maintaining the test reports and the request forms in separate files if they are different documents. Personnel handling these records should be carefully selected and trained to ensure that the institution's procedures for maintaining the privacy of all individuals undergoing screening for the HIV virus are followed without exception.

Information on individuals screened for HIV virus should be maintained in very secure files. In some facilities, this may mean retaining the information in manual files because the health care facility does not have adequate controls on its computerized records to restrict access to this very sensitive information only to those who need to know. Extreme care must be exercised, for if positive test result data falls into the hands of an employer or an insurer, the individual involved may be subject to discrimination in the work place or in obtaining insurance even though no current evidence of disease is present.

Individuals in the screening program will be responsible for seeking any further care that they require, including immunization when such a breakthrough occurs. Therefore, these screening records will be destroyed by shredding at the conclusion of the retention period established by the health care facility in conformance with state law.

### Release of Information

When a health care facility is located in a state with a law requiring reporting of individuals with antibodies to the HIV virus, the facility, staff will specify who is responsible for initiating the reporting procedure. See Appendix A for suggested procedures.

If an individual does not collect his/her test results within one month, the original laboratory report will be reviewed to determine if the results were positive. Reports with positive test results will be transmitted to the individual assigned responsibility under the institution's policies for making a diligent effort to locate the affected individual without violating the affected individual's privacy.

For individuals screened for the HIV virus, information will be released only to the recipient of the service except as required by law. If desired, the individual tested may submit an insurance claim utilizing the laboratory charge ticket which identifies the test only as an antibody test.

## INPATIENT AND OUTPATIENT DIAGNOSTIC AND TREATMENT SERVICES

A health care facility may serve outpatients and inpatients referred by a physician for confirmation of the diagnosis of acquired immunodeficiency syndrome or for the treatment of the various manifestations associated with HIV infections.

### HIV Testing

Each health care facility must adopt a policy specifying whether a special informed consent is to be obtained prior to the performance of a test for the presence of the HIV antibody. Such consents are required by law in some states. When such consents are obtained, they should be filed in the consent section of the health record. See Appendix B for sample consent form.

Health care facilities may need to adopt special policies for HIV antibody testing of patients presenting for care in the emergency service department. Special policies may be necessary because emergency service department staff, laboratory personnel, and other health care workers, especially those who perform invasive surgical procedures, are at some risk if they come in contact with body fluids of HIV virus infected patients.

Moreover, many emergency service department patients are not under the regular care of a physician, so their health status is unknown. Such policies may include voluntary testing with an informed consent; or if the voluntary policy is not sufficiently accepted, the hospital and medical staff may wish to consider a mandatory testing program for the institution in order to protect health care workers.

### Data Collection

Health care data on inpatients and outpatients should be collected following the health care facility's usual data collection procedures, and all such data should be filed in the patient's health record in the order specified by hospital policy.

Although every effort should be expended to maintain the privacy of patients presenting evidence of infection with the HIV virus, meeting their therapeutic needs is the first priority of the health care facility. Health care records are used to provide a medium of communication for current and future patient care and to provide a chronicle of the patient's care for a variety of legitimate reasons. The health care professionals involved in caring for patients infected with the HIV virus must have access to all medical information relevant to the ongoing care of these patients. This information is also required by health care professionals to protect their own health.

The health records of infected patients should not be marked in any special way, for such designations are more likely to cause the privacy of the patient to be violated than routine handling of health records. Special handling efforts also frequently result in the unavailability of records for ongoing care. Information on these patients, therefore, should be maintained following the facility's usual procedures.

Although AMRA recommends that a health care facility should follow its usual policies for maintaining health records on patients who are seropositive for the HIV antibody and those with symptoms of AIDS, state legislation in some states requires that HIV antibody test results be maintained in a special manner. Each health care facility must adopt record maintenance policies which conform with the applicable state laws. In some states the fact that an HIV antibody test was performed is considered confidential, while in other states less restrictive legislation exists.

In states requiring special handling of HIV antibody test reports, it may be necessary for the health record department to adopt a policy of marking such records in an obscure manner to prevent the inadvertent release of information on HIV antibody tests.

### Secondary Records

In addition to the health record itself, patient care information is customarily transferred to a wide variety of secondary records, such as billing records, indexes, or logs.

It is recommended that each health care facility maintain such records using numerical data only. Diagnoses for billing should be transmitted via code number which may require the institution to institute programming or forms design changes to ensure that diagnosis specific information is not printed on billing forms. Billing forms often are processed through employers whose personnel have not been adequately trained in the handling of confidential information.

Disease and operative indexes should be the only other secondary records maintained. These records can be consulted whenever it is necessary to identify patients infected with the HIV virus. Maintaining logs of such patients markedly increases the risk that confidential information will fall into the hands of those without a legitimate need to know.

Health record personnel must make every effort to ensure that disease indexes include every patient treated for AIDS or one of its many manifestations.

Disease indexes should be maintained in conformity with the health care facility's coding policies. AMRA recommends the following policies:

1. The coder should assign the appropriate code whenever a physician lists a diagnosis of acquired immunodeficiency syndrome or a related manifestation.
2. If a physician fails to list such a diagnosis and the documentation in the record clearly indicates that such a diagnosis should be listed, the health record data manager should bring the documentation deficiency to the attention of the physician.
3. When a laboratory report appears in the health record of a patient indicating the patient has antibodies to the human immunodeficiency virus, and the physician lists this finding as a diagnosis, the code 795.8 for "Positive serological or viral culture findings for Human T-Cell Lymphotrophic Virus III Lymphadenopathy-Associated Virus (HTLV/LAV)" will be assigned and the case listed in the disease index.

   The above code will not be assigned without the concurrence of the physician. It is a well-established AMRA policy that abnormal laboratory tests and X-ray findings are coded only when noted in the discharge diagnoses by the physician, because such findings may not indicate the patient has a disease process.

Whenever health records of patients infected with the HIV virus are used in research or quality assurance studies, the health record department staff should take special precautions to safeguard the privacy of these individuals. Care must be taken to ensure that personnel involved in such studies utilize only numbers to maintain their study records, and that records pulled for such studies are well secured.

## Storage and Security

The health care facility is responsible for the data in its possession. Both manual and computer systems create risks: inadequately trained personnel who can inadvertently alter, release, or lose data; perils such as fire or flood which can destroy improperly stored data; and vandals who, for whatever reason, wish to break into files or data banks. The facility must ensure the physical protection of records by persons or organizations receiving, processing, storing, or handling such records to prevent theft, destruction, loss, or other forms of unapproved access. Each health care facility should develop policies and procedures that specify the method of storage for health records along with secondary reports, logs, and files.

AMRA recommends that diagnostic and treatment records of outpatients and inpatients with HIV or its manifestations be housed with the health records of other patients in physically secure areas under the immediate control of the health information manager. Areas housing health information shall be restricted to authorized personnel. Health records must be available and accessible at all times for patient care. When in use within the institution, health records should be kept in secure areas at all times. Health records should not be left unattended in areas accessible to unauthorized individuals such as near the doors of patient rooms or other public areas.

Secondary health records shall be protected with the same diligence as the original health record.

Primary and secondary health records shall be retained in their original or miniaturized form according to legal, accrediting, and regulatory agency requirements, following an approved institutional retention schedule. Destruction will be accomplished by controlled incineration, shredding, or other acceptable means of document disintegration.

## Release of Information

Medical information will be reported as required by state law. Additional information will be released from the records of patients infected with the HIV virus only with an informed written consent (See Appendix B) including at least the following:

- name of individual or institution that is to release the information
- name of individual or institution that is to receive the information
- patient's full name, address, and date of birth
- purpose or need for information
- extent or nature of information to be released (example: AIDS test results or diagnosis and treatment with inclusive dates of treatment)
- specific date, event, or condition upon which authorization will expire unless revoked earlier
- statement that authorization can be revoked but not retroactive to the release of information made in good faith
- date that consent is signed (date of signature must be later than the date of information to be released) and
- signature of patient or legal representative

Information released to authorized individuals/agencies shall be strictly limited to that information required to fulfill the purpose stated on the authorization. Authorizations specifying "any and all information" or other such broadly inclusive statements shall not be honored. Release of information that is not essential to the stated purpose of the request is specifically prohibited.

The release of information from records of AIDS patients or those tested for the HIV virus must be very carefully handled especially in states with restricted access because information about test results may appear in many sections of the health record. Moreover, the use of code 795.8 reflects a positive HIV test, so this information must be considered confidential.

Employees responsible for the release of information function must be carefully trained and supervised to ensure that they consistently comply with hospital policies for release of HIV test results or diagnostic and treatment information on patients infected with AIDS.

Following authorized release of patient information, the signed authorization should be retained in the health record with notation of the specific information released, the date of release, and the signature of the individual who released the information.

Each institution should have a policy for ensuring that no claim for hospitalization benefits for patients with the HIV virus is submitted without ensuring that the patient is aware of the diagnosis, and that this diagnosis must be submitted to obtain hospitalization benefits. The institution's policies should also delineate whether a specific informed consent will be required for release of billing information on patients with the HIV virus.

In response to a subpoena, records on patients infected with the HIV virus will be released as required by state/federal law.

All information released upon the request of a patient with a diagnosis of HIV infection will be clearly stamped with a statement prohibiting redisclosure of the information to another party without the prior consent of the patient. The party receiving the information will also be requested to destroy the information after the stated need is fulfilled.

## Employee Responsibility

All health care personnel who generate, use, process, or otherwise deal with patient-specific information shall uphold the patient's right to privacy. Proven violation of the confidentiality of patient information shall be cause for immediate termination of access to further data and of any employer-employee relationship. This policy shall be made known to all employees at the time of employment, and each employee shall indicate understanding of this policy through a signed statement at the time of employment, kept with the employee's personnel record. Once yearly, an employee having access to health information will be reoriented to the policy and again sign a statement of compliance and understanding.

Every health care facility shall educate all employees on the importance of confidentiality and outline the consequences of violations. In this educational programming, the special sensitivity that must be accorded information about individuals who undergo screening tests or who are infected with the HIV virus must be discussed as well as the adverse consequences that could occur if information is erroneously released.

## Responsibility to the Public

Every health care facility should advise the public of the precautions it has taken to protect the privacy of individuals undergoing screening or already infected with the HIV virus; ensure that no false positive test results are entered into patient health records; and protect the health of its employees. The health care facility should also advise the public that it will comply with all applicable reporting laws such as infectious disease reporting and completion of certificates for vital events.

# CONFIDENTIALITY OF PATIENT HEALTH INFORMATION

A POSITION
STATEMENT OF
THE AMERICAN
MEDICAL RECORD
ASSOCIATION

# Summary of Confidentiality Policies

**Data Collection**

The types and amount of patient information gathered shall be limited to that information needed for patient care. Supplementary data desirable for research, education, etc., may be recorded with the permission of the patient, following explanation of the purpose for which the information is requested.

The collection of any patient data, whether by interview, observation or review of documents, shall be conducted in a setting which provides maximum privacy and protects the information from unauthorized individuals.

Secondary health information that is patient identifiable shall be limited to those indexes required by law or accrediting agencies and to those requested for stated purposes by administration or the medical staff.

**Storage & Security**

The facility must ensure the physical protection of records by persons or organizations receiving, processing, storing, or handling such records to prevent theft, destruction, loss or other forms of unapproved access.

Areas where patient care data are maintained should be restricted to authorized personnel.

Health records must be available and accessible at all times for patient care.

The same security controls which apply for release of the original health record will be applied to facsimiles of the health record.

Secondary health information shall be protected with the same diligence as the original medical record.

Access shall be limited to secondary data identified as sensitive (e.g., physician master code list, abortions performed, etc.).

Hard copies of statistical reports and indexes shall be maintained only in the medical record department and stored in secured files.

Inactive filing records containing discharge diagnoses or coded data will be maintained in secured files.

Computer processed patient, provider, care information shall be protected with the same diligence as the original health record.

Examples:

- identification of author and entry
- use of security codes
- computer facility located in a limited access area

Back up files shall be maintained for all critical hospital information system data off site in a separate geographic location.

Written agreements from computer vendors involved with patient provider health care data:

- mandate the security of computer and data classified as confidential
- specify the methods by which information is handled and transported

**Record Retention**

According to local, accrediting or regulatory agency requirements, primary and secondary health records shall be retained, then destroyed according to an approved institutional retention schedule.

Written agreements from computer vendors specify the length of time patient, provider, health care data will be maintained and in what manner the data will be destroyed.

**Patient Access**

A patient or his representative may have access to his own health record upon presentation of a properly completed and signed authorization, with reasonable notice, except:

- minors governed by legal constraints
- patients adjudicated as incompetent
- situations where the health care provider has determined information would be dangerous to patient or other persons

If the patient's request is denied the provider may:

- provide a summary in a reasonably [illegible] permit inspection by or provide copies of the health records to another health care practitioner who is licensed to treat the same condition as the health care provider and who has been so designated, in writing, by the patient
- include with the health record a statement from the health care provider explaining the reason for refusal

Data corrections shall be made in the form of an amendment without change to the original entry.

**Release of Health Information**

A properly completed and signed authorization is required for release of all health information except:

- as required by law
- direct patient care by authorized personnel [illegible] administrative [illegible] by employees [illegible] information
- request of another health care provider currently involved in the care of the patient
- for medical care evaluation
- for research and education

A proper authorization includes the following data:

- name of institution that is to release information
- individual institution to receive information
- patient's full name, address and date of birth
- purpose or need of information
- extent or nature of information to be released
- specific date, event or condition upon which authorization will expire unless revoked earlier
- statement that authorization can be revoked but not retroactive to the release of information made in good faith
- date consent is signed
- signature of patient or legal representative

The information released shall be [illegible] limited to that only [illegible] required to fulfill the purpose stated in the authorization.

Secondary health information [illegible] released only to those authorized [illegible] by law or by general authorization [illegible] need to know basis.

**Redisclosure**

Released information will be accompanied by a statement prohibiting [illegible] the stated need is fulfilled.

**Employee Responsibility in Confidentiality**

All health care personnel who deal with patient-specific information [illegible] uphold the patient's right to privacy and [illegible] understanding of the consequences of violation.

**Responsibility to Public**

Health information managers have a responsibility for educating the public on patient rights to confidentiality [illegible] to access that information, and to be made aware of the hospital's policies [illegible]

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Senator METZENBAUM. Thank you very much.

I wanted to say that Senator Quayle had an interest in being here this morning, but he is tied up on the floor and cannot be with us. I know he was very interested in your testimony. He has a statement which will be included in the record at an appropriate place.

Ms. Gebbie, you have testified that you support the distribution of voluntary testing funds to states based on population. Would you not agree that the number of cases of AIDS is a better reflection of the infected population than total population, even though it may not be an exact indicator?

Ms. GEBBIE. My concern about using only one indicator, such as number of cases, is that it does not fully reflect the current state of affairs in any one state. And the point of counseling and testing is its role in prevention, and the need for prevention of this disease is as great in a state that has little incidence than in one that has very high incidence today.

The other problem with using reported cases is that what is generally used is the CDC number, and there is considerable migration of patients after they are first diagnosed. So Oregon today shows as having 200 cases reported to CDC, but we have at least another hundred cases of people who have come to Oregon after their diagnosis elsewhere. That similar kind of shift happens in almost all the states in the middle part of the country. Although as a proportionate shift that number may not sound too great to someone from California or New York, it could have a great effect on the funding. We have already experienced that in looking at the funding for AZT, which recently was distributed only on the basis of state-diagnosed cases.

So I would urge looking at some kind of formula that takes into account some other proportionate factor.

Senator METZENBAUM. Something other than population, but not only related to the number of reported cases?

Ms. GEBBIE. That is correct.

Senator METZENBAUM. I understand. A number of states currently have confidentiality laws on the books. Do you feel that they are adequate to ensure confidentiality of test results?

Ms. GEBBIE. Some of them are. I can speak most specifically about our own law recently enacted in Oregon, which is specific to records around HIV seropositivity and provides that the patient must consent for their release except where they are reported to the state health agency as required under law. That is very consistent with the kind of principles pointed out in the Uniform Act that was mentioned by the other witness here. But many, many states have not enacted those laws either around medical records in general or around HIV records specifically.

I also would like to underscore that even if we enact that statute individually in each of the 50 states or a Federal statute, which I think is the swiftest way to accomplish our end, the statute has got to be backed up with education of all parties involved with health information and with the written records, and must be clearly backed up with penalties that will get directly at the person who broke the confidence.

Senator **Metzenbaum**. Your organization would support a uniform state law on confidentiality?

Ms. **Banach**. Yes, we certainly would. We probably may be equally divided in our membership whether that should come from the Federal Government or a state law. We do not have a strong opinion one way or the other. What we are looking for is some consistency.

Senator **Metzenbaum**. How about yours, Ms. Gebbie?

Ms. **Gebbie**. Yes, I would agree with that.

Senator **Metzenbaum**. Ms. Banach, what do you feel is the adequacy of existing state laws on confidentiality?

Ms. **Banach**. I think there is a lot of variability on the adequacy of confidentiality laws. A number of states such as California, Florida, Illinois, Texas, Pennsylvania, and New York have all recently passed confidentiality laws related to the treatment and testing and counseling of AIDS patients. But there are a number of states which have been identified by legal counsel as not having even minimal standards of confidentiality. So I think that we have got the two extremes with a number of states being in between.

Senator **Metzenbaum**. It would probably be better if you had one uniform state law. How long do you think it would take to get uniform state laws enacted by the 50 states?

Ms. **Banach**. According to the national commission which drafts these laws, this commission says that it takes about ten years for the law to reach across the Nation and be passed by every state in a uniform way. It is not an unusual circumstance.

Senator **Metzenbaum**. I can only say, wow, what an impact the AIDS situation would have in a ten-year period.

Given the problem with current state laws and the long time it would take to pass individual laws—I will withdraw the question.

I think it is obvious that we need to do something about confidentiality. I think we have to do something about confidentiality on a uniform basis, and I think it is a question, really, of how you can best attain that goal and how promptly can you attain that goal. I think that is what we are all concerned about.

I want to thank you both for participating and all of the other witnesses who testified today. That concludes our list of witnesses, and we are grateful to all of you.

[Additional material supplied for the record follows:]

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# STATEMENT
# OF THE
# AMERICAN HOSPITAL ASSOCIATION
# BEFORE THE
# LABOR AND HUMAN RESOURCES COMMITTEE
# OF THE U.S. SENATE
# ON THE
# AIDS FEDERAL POLICY ACT OF 1987 (S.1575)

SEPTEMBER 25, 1987

The American Hospital Association welcomes this opportunity to comment on the AIDS Federal Policy Act of 1987, (S.1575). AIDS is one of the most difficult challenges confronting policy makers today. For those individuals infected with the disease, the search for an effective treatment and cure is of the utmost urgency. For those who are not infected, the adoption of effective means of preventing transmission is equally urgent. And for AIDS patients and facilities providing them care, the organization and financing of treatment presents a growing challenge.

Adding to the sense of crisis are the many unanswered questions, and the fear and stigmatization that have grown up around the disease. In developing sound policies to deal with the problem, we cannot afford to let fear guide our actions nor can we afford to ignore the very real concerns that the possible spread of infection engenders.

Any effective response to AIDS must be based upon an understanding of the disease. Data continue to demonstrate that the AIDS virus is relatively difficult to transmit, requiring direct exposure to the blood or other body substances of an infected individual. Consequently, transmission of infection can be prevented through changes in individual behavior. Whether changes needed to reduce the risk of transmission take place depends heavily on the ability and willingness of individuals to alter their behavior. Therefore, efforts to mitigate the spread of the disease must concentrate on educating and counseling both those at risk of transmitting the disease to others and those who may be at risk for exposure. More intrusive measures are unlikely to be more effective because they still depend on cooperation of the individual. Because the AIDS virus is often asymptomatic, it is important that everyone be made aware of the risks. Knowledge is our best weapon against escalation of the disease and fear.

The AHA has undertaken a major initiative to identify effective approaches for both minimizing the risk to the public health and providing humane and compassionate treatment to those who have already been stricken. In 1983, the AHA issued recommended guidelines for hospital employees on the safe management of AIDS patients.

We have recently issued recommendations for the use of "universal precautions" in all hospitals to minimize the risk of transmission in the health care setting. The efficacy of these techniques rests on the use of a barrier such as gloves or protective eye wear when exposure to the blood or other body substances of any patient is expected. By treating all body substances as potentially infectious, both patients and hospital staff can be protected, regardless of whether an individual's infection status is known. We have provided educational materials to all our member hospitals to help health care workers understand the importance of observing these protective measures.

In addition, the AHA has convened a committee of national experts on AIDS and health care delivery to serve in an advisory capacity to help hospitals address the public health needs created by AIDS. We will be issuing a report and recommendations shortly.

As part of our activities to help hospitals and the public cope with the problems of AIDS, we are pleased to submit comments on S.1575. We applaud the Committee's efforts to grapple with the difficult issues raised by the need to prevent further transmission of the disease and by the need to ensure that individuals with the AIDS virus are accorded the same consideration as others who are not infected. This bill represents an important first step in addressing both these concerns.

The bill has three parts:

o Part A would authorize grants to clinics and public general hospitals for the expansion of voluntary AIDS counseling and testing.

o Part B would establish strict confidentiality requirements for records of AIDS testing and counseling, without regard to whether the records were created with federal assistance. Under exceptions provisions, disclosure would be permitted to:

- blood, organ, semen and breast milk banks;
- state health officers, if required by state law;
- spouses or other known sexual contacts (by physician or professional counselor);

- health care workers providing care under conditions that might expose them to significant possibility of infection, as defined by the Centers for Disease Control;
- by order of the Court health officers.

o Part C would prohibit discrimination against qualified persons on the basis of HIV antibody status or diagnosis in employment, housing, public accommodations, and government services, or in the receipt of benefits under any program or activity that receives or benefits from federal financial assistance. Exceptions to the general rule against discrimination would be allowed where there is a possibility of transmission or if disease makes the person unqualified. Penalties are established for violations, including civil money penalties, injunctive reliuf, and private rights of action.

The AHA fully supports the sponsors' efforts to make voluntary testing more widely available. Individuals who may be at risk for infection with the AIDS virus should be encouraged to seek testing and counseling in an environment which assures that the confidentiality of this sensitive medical information will be maintained. By requiring informed consent and allowing for anonymity, AIDS testing programs may have greater success in serving individuals who might otherwise be reluctant to seek consultation; thus, these programs may have a greater opportunity to provide education about necessary behavior changes. It is important to recognize that it is counseling, and not the act of testing, that can ultimately have an impact on reducing risky behaviors and thus, transmission. Even if an individual tests negative for the AIDS virus, appropriate precautions will still be required to prevent future exposure.

Therefore, expansion of testing programs cannot be seen as the solution for protecting public health. Widespread health education activities, targeted to those at particular risk, as well as to the public at large, must be the cornerstone of our efforts to halt the spread of AIDS. The emphasis on thorough pre- and post-test counseling in this bill is an important ingredient in the provision of public education.

The AMA also supports the bill's goal of protecting information concerning AIDS antibody testing from disclosure to anyone without a legitimate need for that information. AIDS test results demand the same confidential treatment accorded to other sensitive medical information. The exceptions to the nondisclosure provisions of Part B appear to have been drafted in the context of handling records in a program designed specifically to provide screening tests and counseling, not in the context of tests performed as part of the diagnosis and treatment of patients in a hospital. Consequently, the exceptions would probably allow disclosure to a patient's physician and direct nursing staff (depending on how the CDC constructs the guidelines), but suggests that test results be kept separately from the medical records. Although the bill's language seems appropriate for governing the handling of information in testing centers, its broad scope will present some problems for hospitals. Care should be taken that the confidentiality requirements outlined in the bill not limit hospitals' ability to appropriately manage patients' care or maintain complete records of the patients' medical conditions.

The Committee is appropriately concerned about the potential for discrimination against infected individuals. The stigma that has been attached to AIDS may have devastating implications for an individual's life. Under no circumstances should a person who is infected with the AIDS virus be denied the consideration accorded to those who have not been exposed. However, in debating the best measures for ensuring that these rights are preserved, it is important to clearly specify protection extended to seropositive individuals. Our major concern with Part C is that it is simply so broad that it is unclear how certain types of situations would be viewed. The ambiguity of the bill makes it impossible to answer basic questions about how it would affect hospital operations. At a minimum, hospitals must retain the ability to determine if they are capable of rendering the type of care needed by particular patients, and they must be able to determine fitness for duty of employees and medical staff without having to rely on an external public health officer to render a medical determination. The AHA supports what we believe to be the goals of this section but believes that greater clarity is required if these goals are to be achieved.

The AHA is committed to helping the nation's hospitals and their communities cope with the challenges presented by the escalation of AIDS. Actions are needed to help prevent transmission of the virus, to protect the interests of individuals who are infected, and most of all, to provide humane and compassionate care for those who have developed the disease. The AIDS Federal Policy Act of 1987 presents an important opportunity to address these issues. We look forward to working with the Committee in the weeks ahead in its efforts to meet the challenge.

## UNIFORM HEALTH-CARE INFORMATION ACT

When a person seeks medical care - goes to a physician or enters a hospital - notes are taken, charts are established, medications are listed. In short, a record of treatment is kept by physicians and hospitals. Who controls those records? Who has access to them? Can someone you don't know see your medical records? These questions are not well answered under current law in almost every state. In addition, the overwhelming use of computers, which store large quantities of information and make access to it almost instantaneous, adds significance to these questions.

At its 1985 Annual Meeting, the National Conference of Commissioners on Uniform State Laws promulgated the Uniform Health-Care Information Act. It provides the needed answers to these questions.

To cover the range of persons and entities that keep records, the Act defines "health-care provider" as any person "licensed, certified, or otherwise authorized by the law of this State to provide health care in the ordinary course of business or practice of a profession." (The definition would exclude pharmacists and others who sell medical devices.) The records a health-care provider keeps on any patient, generally, may not be disclosed to another person or entity without the patient's "written authorization." This is the fundamental, basic rule - the premise with which anybody considering disclosure of such a record must start.

There are exceptions to this fundamental rule, because there are situations in which the need for disclosure without the patient's authorization overcomes the need for individual privacy. They meet specific situations in which the patient's health is not benefited by the basic rule or in which the functioning of health-care providers and health-care facilities would be jeopardized if the basic rule applies absolutely. But exceptions are limited, and the basic rule will govern the large majority of cases.

Exceptions to the rule include disclosure to other persons who are providing health care to a patient; to other persons who must have certain information for health-care education and like activities (but with provisos to restrict re-disclosure); to other persons if disclosure minimizes imminent danger to the health or safety of a patient; or to immediate family members "if in accordance with good medical or other professional practice, unless the patient has instructed the health-care provider not to make the disclosure;..." These kinds of disclosures fit the parameters of protection for individual patient health and maintenance of health-care facilities, records and programs.

The Act also determines the disclosure of records in compulsory processes, whether a proceeding is judicial, legislative or administrative. Again, a patient's consent must be sought in most cases. But, if a proceeding specifically concerns a patient, disclosure may take place under enumerated exceptions.

If a health-care provider discloses any information about a patient, as provided for in this Act, a record of the disclosure must be made. The Act quite specifically governs the form and duration of patient authorization for disclosure and of revocation of such an authorization.

Next in importance to the question of who may have access to a patient's records is the question of the patient's access to his or her own records, and the question of who controls what goes into those records. The Act provides for patient access and for correction of records a patient believes to be erroneous.

Within ten days after a written request to a health-care provider, a patient must have the opportunity to examine and copy his or her own health records. There are circumstances in which a request may be denied. The health-care provider may withhold information on the grounds that it would be injurious to the health of the patient, or that it would endanger the life or safety of another person, for example. But these exceptions are specific and limited, and, like the exceptions to the rule that disclosure of a patient's records to a third person requires the patient's written authorization, they must be treated very cautiously by any health-care provider that denies access to a patient.

Concurrent with a patient's right to examine his or her own record is the power to obtain corrections of an erroneous record. The procedure for obtaining a correction is clearly spelled out in the Act. If the health-care provider refuses to correct the record, the patient must be informed in writing, and the patient still has the right to insert a "statement of disagreement" into the record.

All rights to control disclosure and access to records are accompanied by enforcement provisions. Willful disclosure of health-care information in violation of this Act is classified as a misdemeanor criminal offense, for example. Any violation of the Act may be corrected by civil action, as well. A health-care provider can be compelled to comply with the Act, and may face damages. If a patient alleges that a health-care provider improperly withheld information from that patient, the burden of proving that the withholding of information was proper falls on the health-care provider. The potential penalties suggest that a health-care provider must be careful to comply and to deal with the patient's rights accurately.

Other provisions of the Act concern notice to patients of recordkeeping practices; the health-care provider's right to charge a fee for copying a record; the powers of the patient's authorized health-care representatives; and the health-care provider's recordkeeping obligations. The Act attempts to deal with all issues related to disclosure and access, comprehensively. Given the uncertainty of legal rights, currently, and the potential for damage to individual patient interests because of that uncertainty, the Uniform Health-Care Information Act meets a long neglected need.

Coalition for AIDS Prevention and Education

July 30,1987

Dear Senator:

Since the development of the antibody test in 1984 for the acquired immune deficiency syndrome (AIDS), the national debate on the routine use of the test as a public health tool has escalated. Congress has entered this debate and will soon consider major legislation concerning this issue. Moreover, the Federal government already is implementing policies regarding the mandatory AIDS testing of certain populations (e.g. federal prisoners and immigrants).

We, the undersigned organizations, are contacting you to share with you the attached white paper providing our views and collective expertise on the need for:

o routine counseling when conducting HIV testing,

o confidentiality in the testing process, and

o non-discrimination protections for those who test positive to the virus.

Collectively, we are members of the Mental Health Liaison Group (MHLG), a confederation of scientific, professional, advocacy and voluntary mental health organizations dedicated to improving the quality of mental health services in the United States. Our expertise is based on a wide body of psychological and behavioral research, considerable involvement of our members in testing programs across the country and our experiences as mental health practitioners in clinical settings.

We believe that stopping the transmission of the human immunodeficiency virus (HIV) is an urgent public health goal. Such prevention requires behavioral change which can only be accomplished through education and counseling. Thus, public policy actions aimed at stemming transmission of the AIDS virus must first focus on education and counseling, rather than the testing of individuals. Voluntary HIV antibody testing may be a useful adjunct to counseling but it must be conducted with the most strict and enforceable assurances of confidentiality.

Under the aforementioned circumstances, counseling and testing should be more widely available. Such programs should be offered in family planning, prenatal, sexually transmitted diseases and drug abuse clinics. In order to facilitate the use of this service by stigmatized populations, anti-discrimination protections must be provided at the federal level for all persons testing positive to protect them from adverse actions in employment, housing and health insurance.

We strongly urge your consideration of each of these points in considering public policy options. Should you have any questions about this document, please do not hesitate to contact Alan Kraut, chair, Mental Health Liaison Group, at the American Psychological Association (202/955-7653) or Jim Brennen, chair, MHLG Subcommittee on AIDS, at the American Association for Counseling and Development (202/543-0030).

Sincerely,

Alcohol & Drug Problems Association of North America

Alpha Center

American Academy of Child and Adolescent Psychiatry

American Association for Children's Residential Centers

American Association for Counseling and Development

American Association for Marriage and Family Therapy

American Federation of State, County & Municipal Employees

American Health Care Association

American Hospital Association

American Nurses Association

American Psychiatric Association

American Psychological Association

Association of Minority Health Professions Schools

Child Welfare League of America

International Association of Psychosocial Rehabilitation Services

Mental Health Law Project

National Association of Counties

National Association of Protection and Advocacy Systems

National Association of Social Workers

National Association of State Alcohol & Drug Abuse Directors

National Coalition of Hispanic and Human Services Organizations

National Council of Community Mental Health Centers

National Mental Health Association

National Federation of Societies for Clinical Social Work

Coalition for AIDS Prevention and Education

## AIDS Counseling and HIV-Antibody Testing:
## A Position Paper

Since the advent of the HIV antibody test in 1984, a large-scale, national debate has centered arrund the use of the test as a public health tool. The mental health community has been an active participant in this debate. The following statement reflects the position of a wide range of mental health organizations and is based on a wide body of psychological research data, involvement in testing programs across the country and the experience of mental health practitioners in clinical practice. This statement deals specifically with the psychological issues around testing and does not address issues such as the use of the test by insurance companies or whether health providers should warn individuals who are the partners of HIV positive individuals.

We urge adoption of these principles at all federal agencies.

## Summary

- Preventing the transmission of HIV is a major public health goal.
- Preventing such transmission requires individual behavior change.
- Such behavior change will best be facilitated through a combination of education and counseling.

  **Education** involves providing individuals with information about HIV transmission and risk-reduction.

  **Counseling** involves individualized assessment of risk behaviors, facilitation of effective decision making concerning appropriate behavior change, and resolution of psychological and social problems raised by this process.

- Individuals must also be informed about the the legal ramifications of HIV testing with regard to local and state laws about disclosure, confidentiality and non-discrimination.
- Routine education and counseling should be made available by the federal government to all people who enter family planning, prenatal, sexually transmitted diseases, and drug abuse clinics. Such counseling should also be routinely available at alternative test sites.
- In some cases, HIV-antibody testing will be an appropriate adjunct to such counseling as a strategy for facilitating behavior change or as a source of information necessary for effective decision making. If testing is used, the individual must be given the opportunity to work through psychological issues raised by the testing.
- When individuals are tested for HIV-antibody, privacy protections must be assured. Enforceable protections against discrimination based on HIV seropositivity in housing, employment, public accomodations and federal service should also be assured.
- Sufficient funds should be budgeted to provide effective education and counseling; this includes funding for counselor training, outreach, administration, provision of services, laboratory work and evaluation.

## Background

The role of the human immunodeficiency virus (HIV) antibody test as part of a national AIDS prevention campaign has been the subject of widespread discussion. At a February 1987 conference sponsored by the Centers for Disease Control (CDC), a policy of mandatory HIV-testing received little support from AIDS experts and local health officers from across the country. Routine screening of blood during hospital admission or for people seeking marriage licenses also was rejected because of its high cost and lack of significant public health benefit. At the same time, public health officials voiced support for offering HIV-antibody tests on a voluntary basis to all those who seek family planning assistance, prenatal care, or drug abuse treatment.

The conference participants generally supported education and counseling as part of a national prevention campaign, and agreed that the HIV-antibody test should be an adjunct to education and prevention counseling and not the reverse. It was also clear from the conference that counseling meant different things to different participants. This paper attempts to outline the components of an appropriate education and counseling program associated with AIDS prevention.

## Preventing HIV-transmission through behavior change

The major goal of public health programs concerning AIDS is to prevent the transmission of HIV to others. This requires that individuals refrain from engaging in behaviors likely to transmit HIV. The ultimate goal of educational and counseling programs, therefore, is behavior change, not requiring or encouraging a person to take an HIV antibody test. In order to obtain compliance, solid psychological research show that an individual must voluntarily choose to engage in a behavior change program. Otherwise it is highly unlikely that the individual will adopt the behavior change.

Moreover, the value of testing without counseling is highly questionable. Relevant data has recently been collected from individuals who were screened out from enlistment with the military due to their HIV positive status. Interpretation of a positive test result and counseling are not provided to individuals who have been tested through the military recruitment process. The individuals contacted through this survey continued to engage in high risk activities. Empirical research also demonstrates that adverse social and psychological consequences are associated with knowledge of one's seropositive status, including extreme depression, breakups of relationships, social isolation, and in some case disabling levels of anxiety. In the absence of effective and nontoxic antiviral therapies, knowledge of HIV-antibody status may not always be desirable for the individual.

Privacy Concerns as a Public Health Need

AIDS, ARC and HIV-seropositive status are stigmatizing conditions in our society. The problem is compounded by the prevalence of AIDS among groups that already experience considerable intolerance, e.g., gay men and IV drug users. There is considerable suspicion among persons with AIDS or at risk for AIDS that information about their antibody-status will be unfairly used against them by employers, insurance companies, landlords, and others. The validity of these fears is supported by examples of AIDS-related discrimination, prejudice, and violence. Anonymous testing is preferred, therefore, because it protects clients from discrimination (and is therefore more likely to elicit cooperation from clients with health professionals) while achieving public health goals.

Some states have begun to require the reporting the names of HIV positives to state health departments. In the absence of any real therapeutic intervention, the reporting of individuals who are not sick serves little useful value. Anecdotal evidence suggests that this strategy forces people away from testing programs and into states where mandatory reporting is not required. This situation skews whatever data may be available (i.e., rates of antibody prevalence in a specific geographic area) and exacts an unacceptable human toll. Although it may be useful for epidemiological surveillance to report HIV infections with relevant demographic characteristics, the reporting of a name associated with a test result raises privacy concerns which may interfere with the broader public health goals.

If anonymity is impractical or impossible, testing must be conducted under the most strict guarantees of confidentiality. This should include civil penalties for inappropriate release of testing information. Again, such guarantees are necessary in order to insure cooperation from stigmatized populations. In the design of the counseling and testing program, it is also important to remain sensitive to the fact that the very decision to enter a test site and engage in a program of education and counseling may be perceived to threaten an individual's confidentiality whether the individual ultimately decides to test or not.

In addition, in order for counseling and testing to be effective as part of a prevention campaign, prohibitions against discrimination on the basis of HIV antibody status must be established in law. Such prohibitions against discrimination, should apply to employment, housing, public accomodations and governmental services. Protection must be afforded to those with HIV infections as well as those who may be perceived to be at risk for HIV infection.

### Facilitating behavior change through education and counseling

Routine education and counseling should be available through programs for family planning, prenatal care, drug abuse, or sexually transmitted diseases clinics as well as the existing and future alternative test sites. Although the focus here is on the federally funded programs, counseling should be routinely offered at all testing sites (i.e., private physician offices). All HIV antibody counseling and testing programs should include pre-test education and counseling. No test should be conducted without the informed consent of the participant. Post-test counseling must also be provided. The following outline provides the skeleton of an appropriate counseling and testing program.

I. Education consists of supplying information about means of HIV transmission and methods of reducing risk behavior. It can be accomplished through a variety of channels, including videotape, audiotape, printed matter, group lectures and discussions, and one-to-one interaction between an educator and a client.

II. Pre-test Counseling is necessarily more individualized and includes: risk assessment, recommendations for behavior change and informed consent.

1) **Risk Assessment** consists of reviewing the individual's behavior history sufficiently to determine the presence of risk factors (i.e., high-risk behaviors such as unprotected intercourse and the sharing of unsterilized needles).

2) After individualized assessment, the counselor may make **recommendations for specific behavior changes** for reducing that individual's potential risk of future infection or transmitting the virus to others.

3) **Informed Consent**. Following counseling, the individual should be assisted in making a decision about whether or not antibody testing is appropriate. This discussion will depend upon the individual and the decisions that the individual wishes to

make, e.g. parenting. Because it is important to determine if the individual fully understands the possible benefits as well as the possible negative psychological and social consequences of knowing her/his antibody status, oral informed consent should be obtained before the test is conducted.

III. Testing. If a decision is made to seek antibody testing it may be implemented either through confidential or anonymous testing through the clinic or by referral to an alternative test site.

IV. Post-test counseling is also essential. When the client decides to receive the results, he/she will be individually assessed to determine the extent to which the test result's meaning and implications are clear. When the test result is negative, the individual's understanding of how to prevent future infection should be assessed. When the test is positive, the client must understand how to avoid infecting others; the client also should be assisted in planning to manage the potential psychological and social consequences of seropositive status.

V. Follow-up counseling is recommended in special cases where the assessment indicates that the individual's commitment to behavior change is unclear or where severe psychological distress is evident. At the follow-up session the counselor should work with the individual to reduce resistance to behavior change, and should assist the individual in working through any psychological reaction to the test result. The counselor should be able to provide the individual with referrals for individual psychotherapy, group psychotherapy, support groups, social services, alcohol/substance abuse recovery services, or medical services.

Based on past experience, effective counseling at alternative test sites will require the following: (1) Pre-test: (a) at least 30 minutes of health education in a small group setting (which could be accomplished through video presentations, lecture, or question and answer format), and 30 minutes of individualized assessment and counseling; (2) Post-test: For those individuals who return, a minimum of one-half hour should be scheduled for a post-test counseling session to assess reaction to the test result, risk behavior, and need for additional services; (3) Follow-up: For those who require an additional session, one hour of counseling should be made available with the same counselor.

Budget

The cost of the proposed counseling program at alternative test sites will vary depending upon geographical location, seroprevalence, and the volume of tests to be conducted. The following is an estimate based on expenses associated with each of 10,000 individuals who would receive such a program through an alternative test site in a high risk area. The following is only a model for developing a national program and is based on the San Francisco experience:

10,000 persons - 1/2 hour of health education; 1/2 hour pre-test counseling session.

9,200 persons - Return for 1/2 hour post-test counseling session.

690 persons - Return for 1 hour follow-up counseling session.

The costs of such a program would be approximately as follows:

| | |
|---|---|
| Counseling Services: | $300,000. |
| Counseling Administration | $120,000. |
| Laboratory Work: | $170,000. |
| Health Department Administration: | $ 90,000. |
| Outreach/Advertising: | $120,000. |
| TOTAL: | $800,000. |

On average these costs have worked out to be just over $80.00 per person. The cost of routine counseling at family planning, prenatal, drug abuse and STD clinics must be budgeted separately, based on the volume of cases and the percentage of people who might accept the offer of such counseling. Without testing, such counseling should cost approximately one-half as much as the alternative test site program. Start-up and training costs are not included in this estimate.

## Beyond the Minimum Program

The components of the education and counseling program outlined here reflect an absolute minimum necessary to achieve some degree of behavior change. It is highly likely that extensive additional counseling may be necessary. In addition to more intensive counseling, alternatives such as peer counseling and counseling outside traditional settings must be explored.

## Counselor Training

The counselors in each of these programs would need specialized training. In addition to thorough knowledge of AIDS and health issues, the counselors will also need considerable expertise in mental health issues and techniques of interviewing and conducting individualized assessments. Counselors must be sensitive to the culture/subculture of their clients; this includes communication and language skills. All counselors' basic competencies in these areas should be assessed before they undertake AIDS-related counseling activities.

Program Evaluation

In providing support for a counseling, education and testing program, funds also should be allocated for empirically assessing the effectiveness of educational and counseling programs in reducing high-risk behavior while minimizing psychosocial problems. Evaluation of counseling and education programs should include assessments of changes in clients' AIDS-related knowledge, attitudes, and behavior as a result of participation in the program, as well as assessment of clients' coping and psychological adjustment. Such evaluation will provide empirical data that will permit ongoing improvement in AIDS-related counseling and education programs.

THE NATIONAL
HEMOPHILIA FOUNDATION

TESTIMONY SUBMITTED TO THE

Committee on Labor and Human Resources

United States Senate

Re: S. 1575

(The AIDS Federal Policy Act of 1987)

September 21, 1987

THE SOHO BLDG. • 110 GREENE ST. • RM. 406 • NEW YORK, NY 10012 • (212) 219-8180

Mr. Chairman and Members of the Subcommittee: The National Hemophilia Foundation is pleased to offer its views on S.1575, the AIDS Federal Policy Act of 1987. We commend you and the cosponsors of this legislation for your leadership in responding to this public health emergency. The NHF has also assumed a leadership role in the public health arena regarding AIDS/HIV infection issues; for example, we initiated screening of blood donors in October of 1982. The terrible events in Arcadia, Florida, involving the Ray family underscore the need to address the many issues surrounding AIDS. This legislation moves in that direction and NHF endorses it. For the Committee's information, we have attached our recent statement on the Ray family tragedy. **(see attachment** E).

Let us begin by sharing with the Committee our experience with the effectiveness of comprehensive programs in regard to the AIDS issue. We would like to stress the importance of having programs that are well-organized and staffed, providing pre- and post-test counseling to all individuals at risk of AIDS.

In 1976 Congress authorized the development of comprehensive hemophilia treatment center programs. Over 9,500 persons with hemophilia (nearly 50 percent of the total hemophilia population) are now served by these centers, which provide multidisciplinary services including psychosocial, financial, and vocational counseling, in addition to medical, dental, and orthopedic care. The impact of these programs has been dramatic. (**see attachment** A)

Congress' investment in comprehensive care programs which promote home infusion therapy has paid off by reducing disability, unemployment and the cost of medical care for patients with hemophilia. When the AIDS threat was identified for the population, these established programs provided a basic health care network for the hemophilia community. There were individuals available to hear patient worries, although the resources and expertise were scarce to deal with the problem. The NHF recognized that further program funds were needed to address this concern and supplemental funds for hemophilia were sought and granted.

AIDS: A SERIOUS PROBLEM THAT MAKES THE COMPREHENSIVE TREATMENT CENTERS EVEN MORE ESSENTIAL - As of July, 1987, the number of AIDS cases reported among children and adults with hemophilia was 374. The recognition that AIDS was transmitted through blood products has had a profound effect on families affected by hemophilia. It is a stinging irony that these blood products, which have provided people with hemophilia with a newly-found freedom from pain and disability, have been identified as the source of their vulnerability to AIDS. This crisis has created a need for comprehensive care that is greater than ever before. The hemophilia treatment centers, particularly with respect to the psychosocial care being provided, have served as anchors of support during this critical period. Without them, there surely would have been widespread panic. But now, the need for risk reduction and psychosocial services is increasing dramatically because of the profound impact of the current situation:

- between 33 - 92 percent of persons with hemophilia A have been exposed to HIV,

- between 14 - 52 percent with hemophilia B have been exposed to HIV;

- 10 percent of the sexual partners of persons with hemophilia have been infected with the virus. There have been several cases of these partners, as well as newborns of seropositive women contracting AIDS;

It has now reached the point where it is important to establish adequate programs that will provide for effective risk reduction measures. You should realize that the hemophilia population is a representative of the traditional heterosexual family. Our experience with this microcosm of the general population is useful as you consider effective strategies for changing normally accepted sexual behavior. In order to reduce the transmission of AIDS in the heterosexual population, it is important that accurate information be disseminated rapidly and over time through education and counseling. Accordingly, to fulfill this risk reduction strategy, it is imperative that confidentiality be safeguarded and those involved in risk reduction programs be protected against discrimination. An effective risk reduction strategy absolutely requires that an individual's rights in regard to confidentiality be safeguarded; and that intensive pre-and post-test counseling programs be further developed. Programs need to be extended beyond testing and notification of antibody status. Testing and notification in itself can create anxiety and depression which can be counterproductive in changing behavior; therefore, we are speaking about a commitment to a long-term program.

PROGRESS IN REDUCING THE RISK OF AIDS AMONG PEOPLE WITH HEMOPHILIA - As a result of enormous collaborative efforts between the NHF, the hemophilia treatment centers and other public and private sectors, we have made substantial progress in reducing the risk of AIDS transmission among patients and families affected by hemophilia. Blood donations are tested and blood products used by people with hemophilia are now routinely heat treated to kill the AIDS virus. Based on these advances, blood products used for treatment of hemophilia are now virtually free of HIV contamination.

PROBLEMS IN REDUCING THE RISK OF AIDS AMONG PEOPLE WITH HEMOPHILIA AND THEIR SEXUAL PARTNERS - Even with an established hemophilia treatment center network, the effectiveness of the programs for the prevention of HIV transmission has limitations for the following reasons:

- Confidentiality - There are many hemophilic persons, their sexual partners, and parents of hemophilic children, who refuse to allow testing and counseling to take place until there are laws that will protect the privacy of their medical records and prevent potential discrimination problems.

- Pre- and Post-Test Counseling - We are supportive of the delineation of the components of the pre- and post-test counseling as identified in S.1575. As recommended by the Centers for Disease Control (CDC), based on input from consultants at several recent meetings, wider testing programs must be accompanied by a comprehensive counseling program. Therefore, pre- and post-test counseling should be considered an ongoing process of education and counseling over many years in order to ensure adequate risk reduction. Individuals receiving counseling should include those people in stable relationships, single adults, adolescents, and children.

The hemophilia population is experiencing the threat of another chronic illness (HIV infection) and in some instances, a terminal illness. Ongoing counseling and support needs to be provided to insure the stability of these couples/families who are confronted not only with behavioral changes required for the practice of safer sex but difficult family planning decisions as well.

Also, when counseled on safer sex practices (e.g., abstention and/or barrier methods,) single adults are faced with human dilemmas regarding their ability to develop intimate relationships and participate in the joys of family life.

Another major concern is hemophilic adolescents and young children infected with HIV. They need education and counseling programs tailored to their level of intellectual, cognitive and emotional development. What a young child understands and needs to know will be very different for an adolescent and adult. Accordingly, pre- and post-test counseling programs need to be developed and in place to deal with these special needs. Specialized professional expertise is needed in providing services for adolescents.

Clearly, the education and counseling process will change with age and needs to be available over a lifetime. It is not just a matter of giving information, but understanding how it is received, interpreted, and incorporated into the person's lifestyle.

CONFIDENTIALITY OF AIDS COUNSELING AND TESTING -- The maintenance of confidentiality is a matter of utmost importance to patients with hemophilia, their families, sexual partners, and the hemophilia treatment team for several reasons. Inadvertent release of test results is associated with risk of discrimination, exclusion, expulsion and quarantine for individuals with hemophilia, their sexual partners, and family members. The serious consequences of such disclosure could result in loss of insurability, housing, employment and community life for hemophilia patients and families. Failure to protect confidentiality to the greatest extent possible could result in a patient's decision not to be tested or in a treater's recommendation not to test for fear of the potential negative outcomes of such a decision. Many individuals with hemophilia have already made such a decision, and many treaters have suggested that individuals with hemophilia not be tested, but simply consider themselves antibody positive.

and exercise the necessary precautions to reduce the risk of transmission to sexual partners.

The problem with such an approach is that since April, 1987, there is evidence to suggest that voluntary testing may be beneficial--for the purpose of more effective risk reduction counseling and, for identifying those individuals who do not have AIDS but evidence of asymptomatic HIV infection for experimental therapies. Therefore, we have a situation where testing may be beneficial to the hemophilia population; yet many patients with hemophilia and treaters are not testing due to fear of breach of confidentiality and resulting discrimination.

In their April 1987 medical advisory, The National Hemophilia Foundation recommended that testing be conducted only when the following measures are taken:

A. Signed, informed consent should be obtained, maintained as confidential, and secured apart from the medical record.

B. Results of HIV antibody tests should not be entered in the patient's standard medical or out-patient clinic chart unless: the patient has AIDS or other important HIV-related illness for which knowledge of the result is important to medical management; and patient is being treated with an anti-HIV agent; or another similar reason. Too many persons have access to medical records to guarantee confidentiality. A recently published study from the University of Chicago suggested as many as 30 people see a patient's medical record each day in a typical medical facility. For that reason, most centers have adopted the policy of using numerical codes for samples, and of keeping test results in a separate log book or computer file, under lock and key. THE MAINTENANCE OF CONFIDENTIALITY IS A MATTER OF THE UTMOST IMPORTANCE TO BOTH PATIENT AND THE TREATMENT TEAM.

C. For persons who may be tested, there must be a plan to provide effective information about what the test result does and does not mean. The information must be given in complete detail and with adequate counseling, repetition and follow-up. Although many persons with hemophilia and their family members are well-informed, and although many such persons appear to take the news calmly and philosophically, the degree of anxiety, depression, and the many incorrect assumptions which are regularly seen in this setting require detection and vigilant attention. Although the initial education regarding antibody testing and its result is primarily a medical responsibility, the follow-up must be a team effort and will need to be provided by medical, psychosocial, and nursing staff in order to be maximally effective. Appropriate referral mechanisms for patients experiencing greater difficulty should be put in place in advance of implementing a broader scale testing program.

D. Attention should be paid to the test system used. When a patient is repeatedly reactive with a screening test, Western blot or other specific confirmation may be necessary in order to fully exclude false positives in a population heavily exposed to blood products. Likewise, patients with negative test results will require additional testing and counseling to maintain risk reduction measures until the prevalence of false negatives is defined in this patient population.

E. Treaters will need to continue to pursue a vigorous program of reducing the risks of sexual transmission by HIV antibody-positive individuals. Sensitivity to the patient's preference to keep his sex life private will both foster trust in the caregiver/patient relationship and contribute to an accurate assessment of the individual's safer sex practices. The emphasis will be on education and the use of condoms. With rare exceptions, patients should be vigorously encouraged to include sexual partners in the counseling sessions. It will also continue to be important to offer testing and counseling to spouses and sexual partners of persons with hemophilia. Such counseling and testing will have increased importance before planned pregnancy and post-partum (see Medical Bulletin #36/Chapter Advisory #42). The same consideration regarding informed consent, confidentiality, record keeping and risks of discrimination apply to spouses and sexual partners of persons with hemophilia.

F. Since several recent reports have suggested that the absolute level of T4 (helper) lymphocytes is an important (but non-specific) predictor of clinical outcome, treating physicians are advised to investigate ways to make lymphocyte subset enumeration available, if not already being done. Cohorts of patients with low T4 numbers (e.g., less than 400 cells/ul) may be those initially considered for treatment with experimental anti-HIV agents. As effective drugs with acceptable toxicities become available, the absolute T4 number may be an important criterion for treatment.

Passage of S.1575 would help to ensure protection of confidentiality, which plays an important role in the decision of whether to test. In addition, such protection may help to avoid breaches of confidentiality that are either intentional or those accidental due to negligence.

While this component of the legislation is important, and has the support of The National Hemophilia Foundation, it is equally important to realize that confidentiality can never be fully protected. The average medical record is touched by between 75-80 hospital employees a day. Therefore, there is a justification for requiring that information such as HIV test results be kept apart from the standard medical record and maintained on an "need to know" basis. Ultimate protection of the person with hemophilia and their families would be derived from the non-discrimination part of the legislation prohibiting discrimination as a result of HIV positivity or hemophilia.

The National Hemophilia Foundation also supports the general concept of confidentiality and antidiscrimination as described in H.R. 2575. The National Hemophilia Foundation and Hemophilia Treatment Centers are currently addressing the issue of confidentiality and the notification of sexual partners. We need to weigh the importance of the confidentiality of an individual's test results as opposed to the potential danger posed to an uninformed sexual partner. Every effort needs to be made to engage HIV infected individuals and their sexual partners in the education and counseling process in order to minimize the risk of transmission. Hemophilia treatment center staff work with the individual with hemophilia to encourage them to inform their partner that they are HIV+ or are at risk for being HIV+. This is a very difficult public health problem which the National Hemophilia Foundation is currently addressing.

DISCRIMINATION -- The National Hemophilia Foundation believes that past and present instances of discrimination mandate that federal guidelines be enacted to safeguard the rights of people affected by AIDS and HIV infection.

Persons at risk will not avail themselves of pre- and post-test counseling programs, no matter how well conceived and no matter how accessible, if confidentiality is not insured, thereby eliminating the likelihood of discrimination.

Our risk reduction efforts have revealed that, in the absence of uniform confidentiality requirements, breaches in confidentiality invariably lead to discriminatory acts that severely compromise the well being of patients and their families. Our risk reduction efforts further reveal that patients with hemophilia are not as worried about death and dying as they are about the social ostracism that befalls them and their families. Legislation needs to be enacted that directs organizations (e.g., schools, workplace) to react to the medical evidence that AIDS is not transmitted through casual contact and therefore not continue to react to unfounded fear. Legislation needs to be enacted that prevents local jurisdictions from acting out of ignorance and prejudice when national agencies (i.e., CDC, National Education Association) have offered guidelines based on enlightenment and compassion.

Let us briefly relate to you some startling examples of how even the likelihood of discrimination affects our patients and their families.

A vocation counselor in a major metropolitan center reports to us that many hemophiliacs are lowering their employment expectations. Opportunities for promotion are being avoided because frequently performance review is accompanied by medical review. Advances in hemophilia care have enabled patients to be mainstreamed into the work force with great success but the lack of legal safeguards are causing those who have jobs to guard them carefully and not reach for higher goals.

## II

An honor student in a public high school in the South recently won appointment to a prestigious, eastern private school summer program. The private school, advised that the candidate suffers with hemophilia, required that his HIV status be tested. The student and his family declined the academic opportunity for fear that a positive test result would be disruptive to the student's education; not only the summer program, but also his regular fall program in a state where exclusion has occurred and been widely publicized. Here we have a no-win situation--by providing a positive test result, he would be excluded from school, and by not providing a test result, he was not acceptable. In declining the opportunity and thereby protecting his confidentiality, this student has accepted limitations on his opportunities. We find discrimination not only based on AIDS, but also based on HIV positivity and by virtue of being a person with hemophilia regardless of positivity. We also have found discrimination against family members of those with hemophilia including widows of AIDS victims, spouses, children, and siblings. These individuals should also be protected by the anitdiscrimination provisions.

The much publicized Ray case illustrated the disruption in family life that resulted from a breach in confidentiality that led to discrimination. That this family volunteered to have their children tested meant little to other candidates for testing who see a family shunned from their church, their school, their place of employment, and their community.

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As more and more of the public realizes that AIDS is very much a heterosexually transmitted disease, both persons with hemophilia and their families face increasing incidents of discrimination.

Our experience has shown us, and we expect it [illegible] with you, that current regulations insufficiently protect the child with hemophilia who wants to attend school. Current regulations inadequately protect the person with hemophilia who seeks employment [illegible] positions. Current [illegible] for [illegible] the persons whom they [illegible] among the [illegible] fighting discrimination.

The National Hemophilia Foundation [illegible] discrimination [illegible] We [illegible] support of [illegible]

[illegible]

1. [illegible]

1. [illegible]

- Provides protection against discrimination and a mechanism for exacting penalties for those who fail to comply.

NHF appreciates the opportunity to express its views on this important legislation. We urge the Congress to act expeditiously on it.

ATTACHMENT A"

# NEW TREATMENT CENTER DATA REVEAL "REMARKABLE" HEALTH AND ECONOMIC OUTCOMES

### OUTCOME DATA FROM 31 DMCH FUNDED COMPREHENSIVE HEMOPHILIA CENTERS AND THEIR AFFILIATES

| Outcome Data | Year Before Program (1975) | Tenth Year of Program (1985) | Percent Increased (+) Percent Decreased (−) |
|---|---|---|---|
| No. patients seen at primary centers | 1,783 | 5,606 | +214% |
| No. patients seen at affiliate centers | 329 | 1,641 | +399% |
| No. patients receiving regular comprehensive care | 1,337 | 5,683 | +326% |
| No. patients on self-infusion ("home care") | 514 | 2,517 | +390% |
| Average days/year lost from work or school | 14.5 | 3.9 | −73% |
| Average hospital admission/year | 1.9 | 0.22 | −88% |
| Average days/year spent as inpatient | 9.4 | 1.6 | −83% |
| Percent patients with third party coverage | 74 | 93 | +26% |
| Out-of-pocket expense/patient/year | $ 1,700* | $ 796 | [illegible] |
| Overall costs of care/patient/year | $[illegible]* | $[illegible] | [illegible] |
| Percent unemployed adults | 36 | 9.4 | [illegible] |

*Adjusted for 1985 dollars

April 16, 1987

ATTACHMENT "B"
N.H.F.
INFORMATION EXCHANGE

# AIDS UPDATE

MEDICAL BULLETIN # 49

## MEASUREMENT OF HIV ANTIBODY IN PERSONS WITH HEMOPHILIA

In a previous medical bulletin it was suggested that periodic HIV antibody testing in persons with hemophilia was not indicated, except when performed as part of a research protocol or as part of an assessment related to consideration of a planned pregnancy. This suggestion was based on the opinion that clinical management decisions would not depend on the outcome of the test, thus the test was superfluous. Furthermore, inadvertent release of test results was (and still is) associated with the risk of discrimination, exclusion, expulsion or quarantine.

Because of increasing information regarding the risks of heterosexual transmission of HIV virus, and with the anticipated near-term advent of experimental therapies for persons with HIV infection, it may now be appropriate to institute HIV antibody testing in groups of persons at risk for HIV infection, including those with hemophilia. THE BEST JUDGMENT OF THE TREATMENT TEAM AND THE PATIENT TO BE TESTED (OR HIS FAMILY) SHOULD BE THE DETERMINING FACTORS IN WHETHER TO INSTITUTE PERIODIC TESTING. The state of the law regarding discrimination and confidentiality in the jurisdiction in which the center is located will need to be considered.

Substantial numbers of anecdotal reports reveal that, for the patient the decision-making process, regarding whether or not to be tested, often provokes a crisis. Pre-and post-test counseling and available psychological support is essential. For the individual who proceeds with testing, counseling support must be readily accessible. IT IS RECOMMENDED THAT CENTERS WITHOUT QUALITY PRE- AND POST-TEST COUNSELING SHOULD NOT TEST PATIENTS ROUTINELY. If testing is done, the following measures are strongly advised as routine and integral parts of the testing and counseling program.

A. Signed informed consent should be obtained, maintained as confidential, and secured apart from the medical record.

B. Results of HIV antibody tests should not be entered in the patient's standard medical or out-patient clinic chart unless: the patient has AIDS or other important HIV-related illness for which knowledge of the result is important to medical management; the patient is being treated with an anti-HIV agent; or another similar reason. Too many persons have access to medical records to guarantee confidentiality. Most centers have adopted the policy of using numerical codes for samples, and of keeping test results in a separate log book or computer file, under lock and key. THE MAINTENANCE OF CONFIDENTIALITY IS A MATTER OF THE UTMOST IMPORTANCE TO BOTH PATIENT AND THE TREATMENT TEAM.

C. For persons who may be tested, there must be a plan to provide effective information about what the test result does and does not mean. The information must be given in complete detail and with adequate counseling, repetition and follow-up. Although many persons with hemophilia and their family members are well informed, and although many such persons appear to take the news calmly and philosophically, the degree of anxiety, depression, and

(over)

the many incorrect assumptions which are regularly seen in this setting require detection and vigilant attention. Although the initial education regarding antibody testing and its results is primarily a medical responsibility, the follow-up must be a team effort and will need to be provided by medical, psychosocial, and nursing staff in order to be maximally effective. Appropriate referral mechanisms for patients experiencing greater difficulty should be put in place in advance of implementing a broader scale testing program.

D. Attention should be paid to the test system used. When a patient is repeatedly reactive with a screening test, Western blot or other specific confirmation may be necessary in order to fully exclude false positives in a population heavily exposed to blood products. Likewise, patients with negative test results will require additional testing and counseling to maintain risk reduction measures until the prevalence of false negatives is defined in this patient population.

E. Treaters will need to continue to pursue a vigorous program of reducing the risks of sexual transmission by HIV antibody-positive individuals. Sensitivity to the patient's preference to keep his sex life private will both foster trust in the caregiver/patient relationship and contribute to an accurate assessment of the individual's "safer sex" practices. The emphasis will be on education and the use of condoms. With rare exceptions, patients should be vigorously encouraged to include sexual partners in the counseling sessions. It will also continue to be important to offer testing and counseling to spouses and sexual partners of persons with hemophilia. Such counseling and testing will have increased importance before planned pregnancy and post-partum (see Medical Bulletin # 36/Chapter Advisory # 42). The same consideration regarding informed consent, confidentiality, record keeping and risks of discrimination apply to spouses and sexual partners of persons with hemophilia.

F. Since several recent reports have suggested that the absolute level of T4 (helper) lymphocytes is an important (but nonspecific) predictor of clinical outcome, treating physicians are advised to investigate ways to make lymphocyte subset enumeration available, if not already being done. Cohorts of patients with low T4 numbers (e.g. less than 400 cells/ul) may be those initially considered for treatment with experimental anti-HIV agents. As effective drugs with acceptable toxicities become available, the absolute T4 number may be an important criterion for treatment.

IMPORTANT NOTE: THIS STATEMENT SHOULD NOT BE CONSTRUED TO RECOMMEND COMPULSORY OR ROUTINE HIV TESTING FOR PERSONS WITH HEMOPHILIA. ITS INTENT IS TO ESTABLISH GUIDELINES FOR PHYSICIANS AND CENTERS WHICH HAVE, IN THEIR BEST JUDGMENT, DETERMINED THAT PERIODIC TESTING IS APPROPRIATE.

Attached for your information, is Chapter Advisory # 54 directed to the patient population.

PHYSICIANS: Please distribute this announcement to all providers who treat patients with hemophilia in your area.

CHAPTERS: This Medical Bulletin # 48 is not intended for distribution to your members because the terminology is medically oriented. Therefore, attached is Chapter Advisory # 54, which conveys essentially the same information in lay language.

ATTACHMENT "C"

HEMOPHILIA
INFORMATION EXCHANGE

May 27, 1987

AIDS UPDATE

CHAPTER ADVISORY # 57

## AIDS IN THE SCHOOLS - A MODEL

This is a report of how the small town of Granby, Connecticut dealt with the AIDS in the schools issue in a most sensitive and appropriate manner. The attached reprint of a story published in The New York Times is being shared to illustrate how school officials, parents and classmates can function during and after such a crisis with calm and compassion. This article may be selectively used by chapters and treatment centers when there is potential of people becoming inappropriately alarmed with students in school who have been exposed to HIV or contracted AIDS. For parents in a PTA or sitting on a school board, such an article may give cause for reflection before rash discriminatory acts are performed. It should not be used where the issue does not exist, lest it cause an issue to arise. WE ARE NOT RECOMMENDING GENERAL DISTRIBUTION TO SCHOOL OFFICIALS, BUT WITH POTENTIAL DISCRIMINATION BEING A REALITY AT THE LOCAL LEVEL, YOU MAY FIND THIS USEFUL FOR LIMITED CIRCULATION UNDER CERTAIN CONDITIONS. THE APPROPRIATE USE OF THIS MATERIAL DEPENDS ENTIRELY UPON YOUR ASSESSMENT OF LOCAL CIRCUMSTANCES, AND YOUR BEST JUDGMENT AS TO HOW TO ABATE UNWARRANTED FEARS.

The National Hemophilia Foundation (NHF) stated its position in Chapter Advisory # 35 (November 18, 1985) that "school attendance by children with AIDS presents no risks." Medical Bulletin # 31/Chapter Advisory # 36 (November 25, 1985) suggested that while such a policy concurs with recommendations of the Centers for Disease Control (August 30, 1985 Morbidity and Mortality Weekly Report) and the American Academy of Pediatrics, there can be an expectation of "inappropriate school exclusion and isolation in some areas of the country." While such incidents have not been widespread, they have and continue to occur. These local developments usually capture media attention and often result in hysteria and fear that exascerbate the situation. THERE HAS BEEN NO MEDICAL EVIDENCE OR SCIENTIFIC INFORMATION TO WARRANT A CHANGE IN THE NHF POSITION ON SCHOOL ATTENDANCE. It is important that you share local developments with Christopher Whitney, Coordinator of Education and Preventive Services of the National Resource and Consultation Center for AIDS and HIV Infection (NRCC) so that the NRCC can continually monitor the AIDS in the schools issue.

The Granby, Connecticut story illustrates that while school authorities must contend with an outspoken few who promote exclusion of AIDS patients, strategies can be enacted to support school officials in responsible decision making. This reprint of Michael Winerip's column ("Our Towns" The New York Times, February 27, 1987) further informs on the positive experiences that took place at Kelly Lane Elementary School.

The NHF appreciates the cooperation of Mr. and Mrs. Barnoski, Mr. Winerip and The New York Times in allowing us to share this story.

The New York Times

NEW YORK, NEW JERSEY, CONNECTICUT / FRIDAY, FEBRUARY 27, 1987

**Our Towns**

# *For a 9-Year-Old Dying of AIDS, Acts of Decency*

By MICHAEL WINERIP

GRANBY, Conn.

This is the story of a little town that responded with decency when confronted with AIDS. Not everyone, of course, but most of Granby.

A few were hysterical, vowing they would never send their child to school with an AIDS child. A few demanded 100 percent risk-free guarantees. A few called the school board president, Virginia Wutka, at home after midnight and said they would pay to have the AIDS child educated elsewhere.

The few were noisy. "The few made us miserable," Mrs. Wutka said. The few vowed a petition drive, but Pat Starble, the superintendent, never received theirs. He did get a petition from those supporting the child. "I got hundreds of kind phone calls," said Mrs. Wutka. She was struck by how many older people — people she would have thought were set in their ways — told her to stand up for the AIDS child, that it was the honorable thing.

On Oct. 14, when for the first time since his AIDS was diagnosed, the child was well enough to return to school, officials welcomed him. All agreed the identity of 9-year-old Chris Bernoski — a hemophiliac infected through a blood transfusion — would be kept secret as long as necessary.

His first day back, parents kept 14 children out of the Kelly Lane School. Reporters gathered out front. "Chris didn't want to look like a boy returning to school," said the principal, Robert Barba. "He was so bright — he only took half his books that day." He told his teacher that he walked right by the reporters like normal, so they would not know he was the AIDS boy.

"The kids were tense," said Jo Anne Monroe, Chris's teacher. "They knew Chris was coming back. He came in and they were standing in little groups. So I went up to him while he hung up his coat, put my arm around him and said, 'Boy are we glad to have you back.' And that was it, everyone came up to him, it was their good buddy Chris back."

Chris was put into the first reading and math groups — he had always been in the gifted program. A standout in youth soccer, he played again at recess. He talked of going skiing.

One day, while Chris was out for a checkup, Sheri Dorfman, a social worker, spoke to the class about AIDS. Later, a few wanted to talk with her alone. A boy who shared a snack with Chris years ago asked if he would get AIDS. A girl wondered what a funeral was like.

'The more they talked, the more people realized the right thing to do.'

"The kids were very protective of Chris," said Mr. Barba. "His stamina was not good, he would tire." Once, when it was time for fourth graders to switch rooms, Chris had fallen asleep. During a trip to the Peabody Museum in New Haven, he sat on a bench while the others saw dinosaur skeletons. "They kept coming back, telling Chris what they saw," Mrs. Monroe said.

In soccer, he was no longer one of the best. Some days he just watched. Then he started missing school.

The whole time, the political fight continued. The few wanted guarantees that the AIDS child wouldn't go around biting everyone. The few flew in a $1,000-a-day expert from Nebraska who admitted, when pressed, that he didn't know much about AIDS in the classroom. "The more they talked," said Mrs. Wutka, "the more people realized the right thing to do."

In early November, the board voted 7 to 0 to back Mr. Starble, the superintendent, and allow the AIDS child to stay in school. "Yes, I was proud of Granby," Mr. Starble said. Through weeks of debate, Mr. Starble had never mentioned it publicly, but his daughter Amy was in Chris's class.

By mid-November the boycott fizzled. A first grader had transferred to a private school; one kindergartener was withdrawn.

* * *

Chris's return to class lasted three weeks. He soon grew too weak, and was tutored at home. Feb. 11 was his last day of tutoring. Feb. 18, Chris died.

His parents say they aren't ready to talk, but this week they gave school officials permission to discuss Chris openly for the first time.

The day after Chris died, the social worker returned. She encouraged the students to talk about Chris. Someone remembered how good he was at Mad Math Facts in second grade. Someone remembered how the first grade teacher used to flick water on Chris's head, so Chris would grow faster. Mrs. Dorfman said it's all right to remember bad things, too, and one boy mentioned the time, in first grade, "when Chris kicked a ball in my stomach."

Of Chris's 23 classmates, 20 went to the wake. The father thanked the principal for letting Chris go to school. "He said it meant a lot to Chris," Mr. Barba said.

At the end of "The Brothers Karamazov," a young man dies, and his friend, Alyosha, reminds the rest that after a funeral, it is the custom to eat pancakes, to bring a little of life's sweetness up against death. In this spirit, the day after the funeral, the Kelly Lane School decided to give Chris's classmates a treat. Last Friday instead of work, they got to see the latest Pee-Wee Herman movie, and all the fourth graders laughed, some a little too hard.

ATTACHMENT "D"

**HEMOPHILIA**
**INFORMATION EXCHANGE**

# AIDS UPDATE

November 21, 1985

MEDICAL BULLETIN #31
CHAPTER ADVISORY #36

## ADDITIONAL INFORMATION CONCERNING NHF POSITION REGARDING SCHOOL ATTENDANCE BY CHILDREN WITH AIDS

Recently, you received Chapter Advisory #35 (November 18, 1985) detailing The National Hemophilia Foundation's (NHF) position that "school attendance by children with AIDS presents no risks." Nonetheless, it is expected that these instances of inappropriate school exclusion and isolation will continue in some areas of the country. When such instances arise, it is important that additional information be available to address some of the concerns that may be raised at the local school board level. For this reason, the attached "Recommendations for Providing Education to Students with AIDS" and "General Infomation on HTLV-III Infections - Frequently Asked Questions" are provided for your use when needed. The "Recommendations" provide the basis from which the November 18, 1985 Advisory (#35) was developed. These recommendations are consistent with recommendations issued by the Centers for Disease Control in the August 30, 1985 Morbidity and Mortality Weekly Report.

The attached materials are intended for your information and background when and if it becomes necessary for specific issues to be addressed in your local area. The appropriate use of this material depends entirely upon your assessment of local circumstances, and your best judgment as to how to abate unwarranted fears. General distribution of the attached materials is not recommended.

If there are any specific instances of AIDS-related school exclusion or isolation practices in your area, please inform Christine J. Eastman, RN, NHF, at (212) 219-8180 with carefully documented information.

[illegible]

# THE NATIONAL HEMOPHILIA FOUNDATION
# RECOMMENDATIONS FOR PROVIDING EDUCATION TO STUDENTS WITH AIDS

Recommendations in regard to school attendance by children with Acquired Immune Deficiency Syndrome (AIDS) for local school personnel have been prepared by The National Hemophilia Foundation. These guidelines are in accordance with those of the Centers for Disease Control, which are the most recent scientific data on AIDS, and have been prepared by a panel of 15 experts on AIDS and hemophilia.

Unlike diseases such as measles, influenza, or polio, AIDS is very difficult to transmit. We know that the AIDS virus is transmitted: 1) by sexual contact; 2) when the virus is directly introduced into the body through injection of virus-infected blood products, or by the use of a virus-contaminated needle, and 3) through childbirth. HTLV-III is the virus known to cause AIDS, which arises because the virus destroys the immune system necessary to fight infections. Most persons infected with the AIDS virus develop antibodies to it (HTLV-III antibody positive) and remain well. A small number of people develop symptoms of immune deficiency and are defined as ARC (AIDS-related complex). A still smaller number of people may further develop AIDS.

No evidence to date has shown transmission of AIDS through casual contact. There has been no evidence to date that caretakers of AIDS victims or household members who have shared toilet facilities, eating utensils, bedrooms have been infected. A compilation of 390 such individuals shows no infections transmitted by contacts such as these.

The AIDS virus is fragile; heat, ordinary household bleaches, soap and usual disinfectants quickly kill the virus.

The following recommendations should apply to all children who are well enough to attend school or kindergarten. They are intended to provide school personnel with a framework for the development of programs to meet the needs of all children for whom the public schools are responsible.

1. As a general rule, a child with HTLV-III infection should attend school in a regular classroom setting with the approval of the child's physician and should be considered eligible for all rights, privileges and services provided by law and local policy of each school district.

2. The school nurse could function as: (a) the liaison with the child's physician or hemophilia center; (b) the child's advocate in the school (i.e. assist in problem resolution, answer questions); and (c) the coordinator of services provided by other staff.

3. In the U.S.A. the majority of children with hemophilia are provided comprehensive care by a hemophilia treatment center. It is appropriate for the school providing education to children with hemophilia to set up active communication with the hemophilia center or the private physician who will provide necessary medical support and information relevant to each child.

4. The school should respect the right to privacy of the individual; however, for the protection of the child with AIDS, transmitting the knowledge that the child has AIDS should be considered for those persons with a direct need to know (e.g. principal, school nurse, and/or child's teacher). Those persons may be provided with appropriate information concerning such precautions as may be necessary and should be aware of confidentiality requirements.

5. Circumstances under which some children with AIDS might appropriately be excluded from regular school attendance have been outlined by the Centers for Disease Control:

> "For some neurologically handicapped children who lack control of their body secretions or who display behavior, such as biting and those children who have uncoverable, oozing lesions, a more restricted environment is advisable until more is known about transmission in these settings". (MMWR, August 30, 1985).

6. Each removal of a child with AIDS from normal school attendance should be reviewed by the school medical advisor in consultation with the student's physician at least once every month to determine whether the condition precipitating the removal has changed.

7. A child with AIDS, as with any other immunodeficient child, may need to be temporarily removed from the classroom for his/her own protection when cases of measles, chicken pox, or other illness presenting a hazard to the child are occurring in the school population. This decision should be made by the child's physician and parent/guardian in consultation with the school nurse and/or the school medical advisor.

   Schools generally require that school children be routinely immunized against a variety of diseases (e.g., measles, polio). The status of giving such live virus immunization remains unclear at this time for immunosuppressed children; therefore, the need for vaccination should be discussed with the child's own physician.

8. Realizing that questions concerning hygiene are being raised in the public setting, we recommend, in concordance with the Centers for Disease Control (CDC), that common-sense hygiene maneuvers be applied.

> "Because other infections in addition to HTLV-III can be present in blood or body fluids, all schools and day-care facilities, regardless of whether children with HTLV-III infection are attending, should adopt routine procedures for handling blood or body fluids. Soiled surfaces should be promptly cleaned with disinfectants, such as household bleach (dilute 1 part bleach to 10 parts water). Disposable towels or tissues should be used whenever possible, and mops should be rinsed in the disinfectant. Those who are cleaning should avoid exposure of open skin lesions or mucous membranes to the blood or body fluids". (MMWR, August 30, 1985).

9. AIDS is a sexually transmitted disease (STD). For this reason, it is important that the STD aspects of AIDS be included in the health education curriculum, at both junior high school and high school levels.

Attachment "E"

**HEMOPHILIA**
**INFORMATION EXCHANGE**

August 31, 1987

# AIDS UPDATE

MEDICAL BULLETIN # 55
CHAPTER ADVISORY # [illegible]

(The following is a statement prepared by The National Hemophilia Foundation in response to the events of last week involving the Ray family of Arcadia, FL. If local media contact you in this regard, feel free to share this statement with them and to refer them to NHF for further information.)

## NHF STATEMENT ON RAY FAMILY TRAGEDY

The National Hemophilia Foundation abhors the senseless violence recently promulgated against the Ray family in Arcadia, FL. Three innocent children with hemophilia have been victimized by hysterical and misinformed individuals. These children have been exposed to the Human Immunodeficiency Virus (HIV) through blood products used several years ago but show no signs of AIDS and certainly pose no risk to those with whom they come in contact.

Even if the children involved did have AIDS (which we know they do not), we know that the AIDS virus can be passed to another person only in three ways: by blood transfusion (or shared needles by IV drug abusers); by repeated intimate sexual contact; and by transmission from an infected mother to her child in the uterus during pregnancy. None of these routes is applicable to these children.

It is for this reason that the Centers for Disease Control, the National Institutes of Health, the American Academy of Pediatrics, the Surgeon General of the U.S. Public Health Service, and other public health officers throughout the United States have urged that children with AIDS should stay in school. Again, however, the three children involved in this despicable episode of violence do not have AIDS.

After eight years of the presence of AIDS in the United States, with the last four years in epidemic proportions, NOT ONE SINGLE CASE HAS BEEN ACQUIRED IN THE SCHOOLROOM. Yet three children who do not have AIDS, but who may have been exposed to it in the past, have now had their lives adversely affected for the third time. (The first adverse effect occurred when they were innocent victims of a possibly tainted blood product on which they depend for their lives; the second when they were irrationally barred from church and school in an atmosphere of ignorance and hysteria; and the third and most tragic, when they and their parents lost their home and all their belongings when their home was burned in a suspicious fire.)

(Continued)

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NHF supports the Ray family's request for a full justice department investigation. NHF will continue to vigorously promote the expansion of public education programs that present all of the facts on AIDS, so that episodes such as this will not occur. We will also continue to lobby for more federal support for research programs, and for appropriate legislation which will prohibit discrimination.

A fund in support of the Ray family and their children has been established in Florida. Donations may be sent to: Ray Family Assistance Fund, c/o Peeples, Earl, & Blank, 1225 Second Street, Sarasota, FL 34236.

Physicians: Please distribute this announcement to all providers who treat patients with hemophilia in your area.

Chapters: Please distribute this announcement to your general chapter membership as you consider appropriate.

The City of New York

COMMISSION [illegible]

THE AIDS DISCRIMINATION UNIT

of the

THE NEW YORK CITY COMMISSION ON HUMAN RIGHTS

**UPDATED REPORT**

# AIDS AND PEOPLE OF COLOR:
# THE DISCRIMINATORY IMPACT

August, 1987

Hon. Edward I. Koch
Mayor

Dr. Marcella Maxwell
Chairperson

Alberta B. Fuentes
Executive Director

AIDS and People of Color: The Discriminatory Impact was first written in the summer of 1986. In part it was a reaction to the wealth of information and multiple issues raised at the "AIDS and the Black Community" Conference held in Washington, D.C. in July, 1986 (a joint effort of the Public Health Service and the National Coalition of Black Lesbians and Gays). In the last year many others have written on the subject. This updated report attempts to incorporate new information on the topic.

AIDS continues to touch the lives of so many of us and continues to have a disproportionate impact on people of color. For this reason, the AIDS Discrimination Unit of the New York City Commission on Human Rights believes that the focus on AIDS and the minority communities must continue to be a priority.

There is indeed a second epidemic; it is one of fear, prejudice and discrimination. A grasp of the basic human rights issues permeating this epidemic is imperative if effective, culturally sensitive policy and educational materials are to be developed.

People of color, already burdened by a history of racism and economic inequality, have borne a disproportionate share of the AIDS [illegible] intravenous drug addiction has made [illegible] home, often poorer, minority communities. [illegible] have been shown to be a symptom of the effects of urban poverty and oppression. This helps us to understand the higher incidence of intravenous drug use within some Black and Hispanic[1] communities. But, as with most modes of HIV transmission, it is behavior -.in this case the needle-sharing associated with intravenous drug use - **not one's race or ethnicity**, that is the operative risk factor. Unfortunately, people of color have at times suffered both indifference and stigmatization during the AIDS epidemic (e.g. as the "invisible" component of the gay community, or as the Afro-American or Haitian labelled "AIDS carrier" in the media).

The issues, like the communities of people affected by AIDS, overlap. To enable the reader to obtain a clear understanding of the many separate, yet related aspects of the second epidemic of fear and prejudice, this report is broken into the following categories: women; IV drug users; prisoners; men who have sex with men; testing and stigma; children; and future projections. Human rights advocates and public health officials must meet the challenge of integrating these sometimes divergent concerns and communities in order to develop an effective response to AIDS and AIDS-related discrimination.

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[1] For purposes of this report, the term Hispanic is being used to apply to Latino/a, Chicano/a and other Spanish-speaking communities.

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## Introduction

> The New York City Commission on Human Rights has been dealing with the AIDS crisis since 1983 when an Hispanic grandmother contacted the Commission. Her daughter had just died due to AIDS complications and had left behind several young children. The grandmother had been unable to find a single funeral home that would arrange a burial for her daughter nor had she been able to find anyone willing to help care for the children--no foster home, home care agency, family or friends would offer assistance. This is only one example of the discrimination brought on by the stigma associated with AIDS.

Many people continue to believe that AIDS is a disease which primarily afflicts white, gay men. This assumption is not only incorrect, but dangerously misleading.

In New York City, 55% of all persons with AIDS are Black or Hispanic.[2] This figure is greater than the 44% population figure for Blacks and Hispanics living in New York City.[3] On the national level, the statistical gap is even wider: while Blacks comprise only 12% of the total population, more than 24%

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[2] New York City Health Department, AIDS Surveillance Update, June 24, 1987. Of the 10589 reported AIDS cases, 3297 (31%) are Black, 2534 (24%) are Hispanic, 4694 (44%) are White and 64 (1%) are Other (Native American, Asian etc.) or of unknown origin.

[3] Information from the 1980 census, New York City Health Department.

of those with AIDS in the United States are Black.[4] Similarly, Hispanics, who comprise only 6% of our national population, represent 14% of all people with AIDS in the United States.[5]

The results of recent testing for antibodies to HIV (Human Immunodeficiency Virus, formerly known as either HTLV-III or LAV, and generally accepted as at least a primary cause of AIDS) among applicants for military service reflect the disproportionate impact on Black Americans: more than three times as many Black applicants test positive for HIV antibodies than do white applicants - 3.9 of every thousand Black male and female applicants test positive, compared with only 0.9 out of every thousand white male and female applicants.[6]

Also startling are statistics that indicate that while the average life-span of a white person with AIDS in the United States is 18-24 months, the average person of color with AIDS in expected to live only seven months.[7] Why? This disparity is attributable to a number of factors. It has been suggested that Kaposi's Sarcoma, which strikes White people with AIDS much more frequently than Black and Hispanic persons with AIDS, and carries with it a more optimistic prognosis, accounts for some of the difference in life spans.

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[4] Centers for Disease Control, AIDS Weekly Surveillance Report, United States AIDS Program, Center for Infectious Diseases, July 6, 1987. See also: R. Selik, et.al., "Relative Risks of AIDS for American Blacks and Hispanics," TP.88, poster presentation at Third International Conference on AIDS, June 1-5, 1987, Washington, D.C., see also: "Acquired Immune Deficiency Syndrome among Blacks and Hispanics--United States," Morbidity and Mortality Weekly Report, Vol. 35, No. 42, October 24, 1986.

[5] Id.

[6] D. Burke, et. al., "Human Immunodeficiency Virus Infections among Civilian Applicants for United States Military Service, October, 1985 to March, 1986," The New England Journal of Medicine, Vol. 317, No. 3, p.131, July 16, 1987. Study based on 306,061 recruits screened. See also: "Trends in Human Immunodeficiency Virus Infection Among Civilian Applicants for Military Service -- United States, October 1985-December 1986," Morbidity and Mortality Weekly Report, Vol. 36, No. 18, May 15, 1987.

Another factor affecting the lifespans of these different groups may revolve around the higher percentage of intravenous drug users within the group of Black and Hispanic persons with AIDS. IV drug users may tend to put off seeking medical help longer than others. There are also sociological factors involved. One factor is that more Black and Hispanic persons are unemployed or underemployed than Whites. People in this situation may not have access to workplace-funded medical insurance. There may be no family doctor and people in such a situation may thus have to rely on hospital emergency rooms for medical care. Consequently many people of color are, for a variety of reasons, neither diagnosed nor treated for AIDS-related conditions until the disease reaches an advanced stage. Hence, an historical problem - the absence of proper medical care for racial and ethnic minorities and the poor - has critical implications in the AIDS epidemic.

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[7] Conversation of July 28, 1983, with Dr. Wayne Greaves, Chief of Infectious Diseases, Howard University Hospital.

## Stigma and Designated Risk Groups

The stigma connected with AIDS has combined with already existing prejudices in our society to produce widespread discrimination against those who have the disease as well as those associated with AIDS in any way. Thus people with AIDS, in addition to coping with a catastrophic illness, often face abandonment by family and friends, the loss of their jobs and health insurance and eviction from their homes. Many are denied critical services such as transportation by ambulance, or emergency medical and emotional care. The range of discrimination suffered by this group is phenomenal.

Additionally, there is an ever growing group of people who do not have AIDS but who are nevertheless targeted for AIDS-related discrimination: those who are perceived to be "AIDS risks". This group includes IV drug users, homosexuals, prostitutes, Haitians, homeless men and women, the poor, racial and ethnic minorities, people who test HIV positive and anyone who loves and cares for people with AIDS - family members, health care workers, spouses, lovers, children and friends of the person with AIDS.

Initially, persons whose behavior put them at a risk for HIV infection were categorized on the basis of "risk group" rather than "risk behavior." Unfortunately risk definition based upon identity has caused confusion and discrimination. Persons who do not identify themselves as members of a "risk group" (i.e., men who participate in sexual activity with other men but do not identify as gay or homosexual, recovered IV drug users, transfusion recipients, women who are infrequent participants in sexual activity with men, etc.) may not realize their past or intermittent behavior put them at risk of HIV infection and so may not respond to educational efforts or follow risk reduction guidelines. The World Health Organization and the New York City Health Department have revised their risk categories to more precisely reflect risk **behavior**. Unfortunately, the media has not responded accordingly. The original "risk group" categorization has led to stigmatization of those who either are members of or are perceived to be part of these "groups" (homosexuals, Haitians, prostitutes, etc.).

Too often in discussions of public policy related to AIDS, we hear that human rights and public health are in conflict. This creates a false dichotomy. In the midst of something as dire as an epidemic, drastic public health measures may be necessary. But where fundamental constitutional rights are at stake (liberty, freedom from unlawful searches (blood tests), privacy), public policies that intrude upon these rights must be shown to be sound (meaning that they are necessary to serve "compelling" governmental interests).[8] Given the nature of the AIDS epidemic, good public health policy must consider civil rights because the epidemic will be driven further underground if we don't protect these rights. Where widespread stigmatization and discrimination exist, all people, and especially those we most want to reach, are understandably reluctant to seek needed information, diagnosis and treatment. Public health officials, including Surgeon General Koop, have noted that the stigma and discrimination associated with AIDS are among the biggest impediments to implementation of an effective public health program to combat AIDS and HIV transmission. Public health and civil rights are natural and necessary allies in the fight against AIDS.

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[8] Public health measures may also be subject to constitutional challenge if they can be shown to be irrational. The key is whether the proposed policy actually does (or will) protect public health or safety. See generally: Closen, Connor, Kaufman and Wojcik, "AIDS: Testing Democracy", 19 John Marshall Law Review, 837, 892 (Summer, 1986); Merritt, "The Constitutional Balance Between Health and Liberty", AIDS: Public Health and Civil Liberties, A Hastings Center Report Special Supplement, December, 1986.

IV Drug Users

In New York City, IV drug users constitute 33% of all adult metropolitan AIDS cases as of June 24, 1987.9 An additional 5% of adult metropolitan AIDS cases were men who both used IV drugs and had unprotected sex with other men.10 While drug users come in a variety of racial, ethnic, sexual and economic groups, it is known that Blacks and Hispanics comprise a large percentage of IV drug users with AIDS. Current statistics indicate that 80% of all IV drug users with AIDS in the United States are [illegible]

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9 NY City Health Department, AIDS Surveillance Update, June 24, 1987.

10 Id.

Hispanic.[11]

New data suggests that the current case definition of AIDS used by the Federal Centers for Disease Control may not accurately reflect the prevalence of HIV infection among IV drug users.[12] Since 1981, IV drug user deaths in New York City have increased dramatically--an average of 30% each year.[13] The New York City Health Department has conducted several investigations to study this trend and they have concluded that the increase in mortality among IV drug users is caused by HIV-related disease which does not qualify as AIDS under the CDC definition. They believe these severe manifestations of HIV infection are underestimated among IV drug users by a factor of 50 to 100%.[14]

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[11] Centers for Disease Control, AIDS Weekly Surveillance Report, United States AIDS Program, Center for Infectious Diseases, July 6, 1987. Of the 6164 cases reported among IV drug users, 3126 (51%) are Black and 1827 (30%) are Hispanic.

[12] B. Truman, et. al., New York State Dept. of Health, "Surveillance for HIV-related disease that does not meet the CDC AIDS Case Definition: Upstate New York," WP.61, poster presentation at Third International Conference on AIDS. See also: S. Weiss, et. al., "Mortality, AIDS Incidence and Immunologic Abnormalities Among Intravenous Drug Abusers (IVDA) in New York City (NYC): A 5-Year Prospective Study," TP.87, poster presentation at Third International Conference on AIDS.

[13] Joint Subcommittee on AIDS in the Criminal Justice System of the Committee on Corrections and Committee on Criminal Justice Operations and Budget of the Association of the Bar of New York, AIDS AND THE CRIMINAL JUSTICE SYSTEM: A PRELIMINARY REPORT AND RECOMMENDATIONS, June 12, 1987, pp. 8-9; See also, NYC Dept. of Health, "Increasing Mortality in Intravenous Drug Users: Its Relationship to the AIDS Epidemic in New York City", 5 City Health Information No. 13, 2-3 (Special AIDS Issue No. 4, August 13-27, 1986).

[14] Conversation with Dr. Rand Stoneburner, New York City Health Department, July 30, 1987. See also: AIDS AND THE CRIMINAL JUSTICE SYSTEM: A PRELIMINARY REPORT AND RECOMMENDATIONS, op. cit.

Classification becomes an issue when attempting to obtain many social service benefits. In order to qualify for accelerated SSI and Medicaid payments, for example, individuals who are ill with HIV-related infections must meet the CDC case definition of AIDS. If an individual does not meet the CDC case definition of AIDS, he or she may wait up to two years to qualify for and obtain benefits. It is unlikely that a person who is too ill to work due to HIV-related illness will live through the waiting period.

There are an estimated 250,000 IV drug users in New York State, 200,000 of whom live in the New York City metropolitan area.[15] Although there are over 200 drug treatment programs in New York City,[16] the New York State Division of Substance Abuse Services reports there are 1,724 persons on the waiting list for residential, drug-free (non-methadone) treatment programs. There are 353 persons on the waiting list for methadone maintenance programs.[17] IV drug users seeking treatment in NYC may wait from three weeks to six months before admission.[18] Complicating matters, some of these treatment centers refuse to accept into their programs persons with AIDS or ARC or those who test HIV positive. Reports have come to the Commission that some drug treatment programs require potential residents to "prove" they do not have AIDS by testing HIV negative.

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[15] Id. at 5.

[16] Telephone conversation, July 23, 1987, with Alan Kott, Assistant Deputy Director of Substance Abuse and Evaluation, New York State Division of Substance Abuse Services.

[17] Id.

## Women

AIDS is also a women's issue. It has a particularly devastating impact on women who have the disease themselves or who have children or other family members who have AIDS or live in communities beset by the disease, and who care for the people who are sick with the manifestations of HIV infection.

Women are most often the caretakers of the family and of the sick. Consequently, when a woman becomes ill or dies, particularly in poverty-stricken communities where women are often the economic base as well, the whole fabric of family and extended community can be shaken. Volunteerism is increasingly seen as the answer to the escalating cost of caring for these with AIDS and ARC. However, the enormous burden this illness already places on those communities with the least support and resources to handle such a crisis must be recognized.

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[18] In a telephone conversation on July [illegible], 1987, Bill Griffin, Regional Supervisor, Contract Management, NY State Division of Substance Abuse Services, stated that the average wait for entrance to a residential drug-free program was three weeks. In a telephone conversation on July 23, 1987, John Kemp, Director of New York State Division of Substance Abuse Services Brief Therapy Center, stated that in his personal experience, the waiting time for treatment in New York City varies from several weeks to three months or more. A telephone call to Beth Israel Medical Center revealed that they run 23 outpatient drug treatment programs. The wait for treatment in some of the programs is three to six months. (Telephone conversation with Frank King, Intake Coordinator, July, 1987)

Women also remain critically uninformed about how to protect themselves from AIDS. As of June 24, 1987, women constituted 10.4% (1096) of the reported AIDS cases in New York City.[19] Out of this total, 84% are women of color.[20] While 61% of these women state that they have used IV drugs, 22% contracted AIDS through sexual activity with a partner who was infected with the HIV virus (generally through IV drug use).[21] Nationally the number of cases of women with AIDS reported to the Centers for Disease Control has increased more than fifteenfold from 162 in the end of 1983,[22] to 2569 as of July, 1987.[23] It is projected that by 1991 AIDS will be the largest killer of women of childbearing age in New York City. According to the Centers for Disease Control, because of IV drug use and the incidence of HIV infection within some Black communities, statistically a Black woman is 13 times more likely to have AIDS than a White woman.

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[19] New York City Health Department, AIDS Surveillance Update, June 24, 1987.

[20] Id. This number includes: 560 Black women (51%), 352 Hispanic women (32%), and 4 women (1%) whose race is other or unknown.

[21] Id.

[22] Guinan and Hardy, "Epidemiology of AIDS in Women in the United States, 1981 Through 1986," Journal of the American Medical Association, Vol. 257, No. 15, pp.2039, 2040, April 17, 1987.

[23] AIDS Weekly Surveillance Report, op. cit.

For the same reasons (incidence of HIV infection within communities hard hit by intravenous drug use) an Hispanic woman is 11 times more likely to have AIDS than a White woman.[24]

Unfortunately, it is difficult for a woman to determine if her male sexual partner is at risk or is HIV positive. The stigma of a man's admission that he is bisexual or has engaged in homosexual activity and the difficulty in determining if a sexual partner has been an occasional IV drug user serve to make risk factor identification elusive. Therefore use of condoms as a precaution is imperative for women whose partners may be at risk. In addition, many men (recovered drug users, infrequent participants in homosexual activities, blood transfusion recipients, etc.) may truly be unaware that they are HIV carriers since the majority of such persons may remain without symptoms of AIDS-related illness for months or years after infection.[25]

Historically, women have often been blamed for the spread of sexually transmitted diseases.[26] Both the media and leading researchers improperly lump together discussions of sexually active women, prostitutes and IV drug users -- as though all sexually active women are prostitutes, and all prostitutes are IV drug users. Race or sex stereotyping about drug users, prostitutes, sexually active women and poor women only compounds the problem.[27]

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[24] "Acquired Immune Deficiency Syndrome (AIDS) among Blacks and Hispanics--United States," *Morbidity and Mortality Weekly Report*, Vol. 35, No. 42, October 24, 1986. *See also*: Richard Goldstein, "AIDS and Race," *Village Voice*, Vol. XXXII, No. 10, March 10. 1987,p. 23.

[25] *See*: "Provisional Public Health Service Inter-Agency Recommendations for Screening Donated Blood and Plasma for Antibody to the Virus Causing Acquired Immunodeficiency Syndrome," *Morbidity and Mortality Weekly Report*, Vol. 34, No. 5, **, 1985.

[26] Allan M. Brandt, *No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880*, Oxford University Press, 1985.

Women in need of medical care or information regarding reproductive care are highly vulnerable to abuse, and issues of informed choice, confidentiality and informed consent at such a time become quite serious. Women of color and poor women in general are subject to situations with far reaching complications when seeking medical help or prenatal care. It has been alleged that in certain parts of the country women are routinely screened for HIV antibodies with neither their knowledge nor their consent. Talk of the mandatory sterilization of, or abortions for, the seropositive women thus identified has made the rounds of "health committees" nationwide. These recurring indications of disregard for the rights of women are quite alarming.

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[27] For further discussion *see*: P. Alexander, "Prostitutes are being Scapegoated for Heterosexual AIDS", *Sex Work*, Cleis Press (1987), p.248; P. Maher and A. Tallmer, "The Typhoid Mary Debate", *The Connection*, September 2, 1985, p. 26. These articles point out that undue attention has been placed on prostitutes (sex industry workers) as a "risk group" for AIDS. At least in the U.S., this focus is misleading and stigmatizing. In almost all instances where a woman who had worked as a prostitute tests antibody positive, she has reported a recent history of intravenous drug use. Prostitutes that do not use intravenous drugs (estimated to be the vast majority (85-90%)) do not appear to be testing HIV antibody positive at a rate higher than other sexually active women. Interestingly, many studies indicate that most prostitutes routinely use condoms (and have for years) for all sexual contacts with customers. Intravenous drug use, certainly a significant risk behavior, is often eclipsed. Instead, the emphasis is inappropriately placed on prostitution.

## Teenagers and Children

The high rates of pregnancy and sexually transmitted diseases among minority teenagers are irrefutable.[28] This has tremendous implications regarding the spread of AIDS. Even if these young women use birth control methods such as the pill or a diaphragm and thus feel "safe" they remain at risk for sexually transmitted diseases, including AIDS. Because the HIV virus is definitely known to spread to women through vaginal and anal intercourse, generalized use of condoms must be encouraged.[29] AIDS education aimed at young men and women has been undertaken by both the City and community groups; but it is likely that even greater efforts must be undertaken. The HIV virus is not willing to wait for the community's timely response; it is spreading now. In New York City today, AIDS is the fourth leading cause of death for young women from ages 15-24.[30] To fail to address these issues is to ensure that more children and teenagers will become infected and die of AIDS-related causes.

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[28] According to the New York City Health Department, there were 13,168 live births to young women under the age of 20 in 1986. Of this number, 6251 (47.5%) were Black, 5269 (40%) were Hispanic, 1504 (11.4%) were White and 144 (1%) were American Indian, Chinese, Filipino or "other non-white."

[29] C. Everett Koop, Surgeon General's Report on Acquired Immune Deficiency Syndrome, October, 1986. See also: Constance Wofsy, Editorial, "Human Immunodeficiency Virus in Women," Journal of the American Medical Association, Vol. 257, No. 15, pp. 2074, 2076.

[30] Telephone conversation with Dr. Singh, (July, 1987) New York City Health Department, Bureau of Health and Statistics Analysis.

As AIDS spreads in the adult population, the impact on our next generation is already apparent. Between June 1981 and July, 1987, 525 cases of children with AIDS (ages 0-12) were reported to the National Centers for Disease Control. Of this number 414 (79%) are children of color.[31] In New York City there are 187 children known to have AIDS - *90*% are Black or Hispanic.[32] NYC Department of Health estimates indicate that in 1987 alone, approximately 1200 children may be born with HIV infection.[33] According to Centers for Disease Control figures, a Black child is 15 times more likely to be born with AIDS than a White child and an Hispanic child is 9 times more likely to be born with AIDS than a White child.[34]

Some of these children will develop AIDS and die in infancy, but most will not. Problems abound for the child who is seen by others as an AIDS risk. The Commission has received reports that even the healthy children of people with AIDS were denied housing, expelled from school and refused public services. What will become of children with AIDS or children who have the HIV virus? Will they be able to obtain foster care? Finding foster

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[31] 280 (53%) are Black; 130 (25%) are Hispanic; and 4 (1%) are other or unknown. *AIDS Weekly Surveillance Report*, *op.cit.*, July 6, 1987

[32] 107 (57%) are Black; 62 (33%) are Hispanic; and 18 (10%) are White. New York City Health Department, *AIDS Surveillance Update*, June 24, 1987.

[33] Conversation with Dr. Polly Thomas, New York City Dep't of Health, August 4, 1987.

[34] "Acquired Immune Deficiency Syndrome (AIDS) Among Blacks and Hispanics--United States," *Morbidity and Mortality Weekly Report*, Vol. 35, No. 42, October 24, 1986.

care for any child is a difficult task; it is much more difficult for the child with AIDS. And what of schooling?[35] Will the City be able to continue to check the public's fears or will AIDS panic go on to foster quarantine, tattoos and confinement for this vulnerable segment of society?

The recent fire-bombing of a proposed home for "boarder babies" in New York's Queens County suggests that AIDS fear and racial bias may represent a growing problem in some communities. In New York City many children with AIDS, though not acutely ill, spend extended periods of time, in some cases their whole lives, in hospitals. Some are still too ill to go home, others have no home because their parents have died from AIDS. It has proven almost impossible to find foster placement for HIV-infected children.

## Prisoners

The vast majority of prison inmates are racial and ethnic minorities and 60% of the inmates in New York State prison facilities acknowledge a history of IV drug use.[36] As of January 15, 1987, AIDS was the leading cause of death in New York State prison facilities, causing more than 50% of the deaths.[37] Here too the HIV virus may be spreading[38] as these men and women have sexual relations and use IV drugs while incarcerated. In addition many inmates have spouses who, through conjugal visits or sexual relations after prisoners are released, are directly affected and placed at risk of contracting AIDS. While the Commission in no way advises against conjugal visits, it is obvious that prisoners and those who may be sexually active with prisoners must receive education about AIDS transmission and have access to condoms. NYC's Health Commissioner, Dr. Stephen Joseph, in an effort to stem the tide of HIV transmission within the prison system, has publicly called for the distribution of condoms to prisoners.

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[35] The City of New York successfully defended the rights of children with AIDS to attend public school. District 27 Community School Board v. Board of Education, 130 Misc. 2d 398, 502 N.Y.S. 2d 325 (Queens Co. 1986).

[36] According Steven Del Giacco, Public Information Director at the New York State Commission of Corrections, there are 40,000 inmates in New York State prison facilities. As of September, 1986, 50% are Black, 28% are Hispanic, and 22% are White and other. (Conversation of July, 1987)

### Men who are sexually active with other men

Of the 5,885 homosexually active men who have been diagnosed with AIDS in New York City, 35% (2,041) are racial minorities, primarily Blacks and Hispanics.[39] Of an additional 489 men who were both sexually active with other men and used intravenous drugs, 61% (296) are men of color.[40] Nationally, of Black and Hispanic men stricken with AIDS, over 50% are among men who were homosexually active.[41] The continued assertion that AIDS only affects gay white men and other efforts to ignore the existence and needs of Black, Hispanic, Asian and Native American gay and bisexual men -- by the gay community as well as the Black, Hispanic, Asian and Native communities -- reinforces racial and sexual stereotypes. The AIDS statistics prove that these men do exist. It is likely that special educational efforts directed toward the needs of these men -- and especially gay and bisexual minority teenagers -- may be necessary.

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[37] Approximately half of the inmate AIDS cases in federal and state prisons occurred in NY State prison facilities. As of January 15, 1987, of the NY State prison cases, 335 (97%) are male, 12 (3%) are female; 46% are Hispanic, 39% are Black, and 14% are White. D. Morse, et. al., "AIDS in New York State Prison Inmates," THP.70, poster presentation at Third International Conference on AIDS.

[38] In 1985 there were approximately 30+ inmates with AIDS at any given time, while in 1986 that number jumped to 50+ inmates with AIDS. The upward trend has continued. In 1987 there are 80+ inmates with AIDS at any given time. Steven Del Giacco, Public Information Director at the New York State Commission of Corrections reports that in the New York State and City prisons and jails and the county jails there were 23 inmate deaths from AIDS in 1983, 68 AIDS-related deaths in 1984, 107 AIDS-related deaths in 1985 and 146 AIDS-related deaths in 1986. (Conversation of July, 1987)

The National AIDS Network head of Minority Affairs, Gilberto Gerald, described the dilemma facing Black and Hispanic people with AIDS:

> Not only is homosexuality a taboo topic in both the Black and Hispanic communities, but intravenous drug users have no political constituency either. AIDS

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[39] 1046 (18.5%) are Black, 910 (16.5%) are Hispanic, and 47 (1%) are other or unknown. New York City Health Department, AIDS Surveillance Update, June 24, 1987.

[40] Id. 166 (34%) are Black, 129 (26%) are Hispanic, and 1 (.2%) is other or unknown.

[41] The New York Times reported that of the 764 Black male cases of AIDS per million Black and Hispanic population, 379 were "gay or bisexual men who are not intravenous drug users". Of the 730 Hispanic male cases of AIDS per million Black and Hispanic population, 389 were among gay or bisexual men who are not intravenous drug users. W. Schmidt, "High AIDS Rate Spurring Efforts for Minorities", New York Times, August 2, 1987, p. 1. Source: Dr. Roger Bakeman, Dept. of Psychology, Georgia State University. Based on CDC data from April 6, 1987.

patients are a minority within a minority.[42]

Like Black and Hispanic men generally, gay and bisexual men have historically been stereotyped as "oversexed" and "promiscuous". This is, of course, not true but the stigma remains and has been exacerbated by the AIDS epidemic. Stereotypes aside, it must be remembered that it is *behavior*, i.e. *how* you do what you do - safe or unsafe sex - rather than *how many* people you do it with, that is the actual risk factor.

## The Scope of AIDS-related Discrimination

Fears about sex, death and disease are deeply ingrained in our society.[43] These fears readily combine with pre-existing prejudices against racial and ethnic minorities, homosexuals, immigrants, women and drug users. The resultant brew can be summed up in one sentence: **AIDS does not discriminate, but people do.** People with AIDS and even those simply "suspected" of having AIDS have been thrown out of their homes,[44] have seen their healthy children barred from entering schools and obtaining day care services, have lost their jobs, have been denied ambulance service and essential medical attention, and have been denied access to places of public accommodation such as restaurants, stores, bars, hospitals and clinics. Since the early days of the AIDS crisis, signif-icant headway has been made but the Commission continues to receive reports of problems encountered by people with AIDS in all these areas. For instance, while it may seem that children with AIDS or ARC can now enter New York City schools, this decision applies only to public schools. Recently the Commission encountered fierce determination on the part of one private school to bar a child whose aunt had AIDS from entering classes.

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[42] Id. at 27.

[43] Allan M. Brandt, "AIDS: From Social History to Social Policy", 14 *Law, Medicine and Health Care* 231 (December, 1986).

[44] The New York City Human Resources Administration's AIDS Management Unit currently estimates that they provide housing assistance to approximately 473 persons with AIDS (as of June, 1987). Patrick Hacker, Director of Supportive Housing for the AIDS Resource Center, confirms that inadequate housing and homelessness are serious and growing issues for people with AIDS. This situation is in large part a reflection of discrimination and stigma: when people with AIDS are denied access to nursing homes, evicted from their homes or shunned by family and friends, they are left with nowhere to go.

To cite just one example of the AIDS backlash on an identifiable group, consider the devastating impact of AIDS-related discrimination on Haitians. Despite the fact that Haitians have been removed from the CDC's list of AIDS risk groups, the stigma remains. Reports from Haitian community workers indicate that in some areas the unemployment rate for Haitians is twice that of other Black workers[45]. Why? Many Haitians feel this situation is directly attributable to AIDS. Particularly hard hit have been domestic workers, who are generally female and often undocumented. Haitian children have been beaten up (and in at least one case, shot) in school; Haitian store owners have gone bankrupt as their businesses failed; and Haitian families have been evicted from their homes.

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[45] Leonard A. Fisener, Fair Employment Report (formerly Civil Rights Employment Reporter), December, 1983 at p.206.

The problem of discrimination against this community is not new, but unfounded fears about AIDS have surely escalated the intensity of prejudice directed against Haitians. The same is true for the various groups (gays, IV drug users, prostitutes, etc.) now linked with AIDS in the public's consciousness.

**The HIV Antibody Test**

The HIV antibody test detects the presence of antibodies to Human Immunodeficiency Virus, an agent generally thought to cause AIDS. A positive test result does not mean an individual has AIDS or will get AIDS; it indicates exposure to a virus associated with the syndrome. Rather than rely on use of mandatory HIV antibody testing, New York City Health Commissioner Stephen Joseph has determined that at this time our most effective approach is a widespread program of effective AIDS prevention education combined with counseling-based HIV antibody testing as an option. As Commissioner Joseph stated in a recent public address:

> Virtually all public health officials from areas of highest AIDS prevalence are agreed that forcing people to learn their serostatus when no treatment is available, and unless confidentiality can be assured, would be unwise and counterproductive.[46]

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Remarks by Commissioner Joseph entitled "Planning for AIDS in New York City" presented to the Association for a Better New York Community Council of Greater New York, April 21, 1987.

[46] Remarks by Commissioner Stephen Joseph entitled "Planning for AIDS in New York City" presented to the Association for a Better New York, Community Council of Greater New York, April 21, 1987.

Everyone is appropriately concerned about preventing further HIV transmission. However, calls for mandatory testing offer a false sense of security.[47] In the absence of a cure and vaccine, it is primarily behavioral changes (avoidance of high risk behavior) that will prevent further spread of the virus. Required testing of large segments of the population would be enormously costly - diverting large amounts of scarce funds and labor away from much needed education and drug treatment programs. At a recent national gathering of AIDS experts sponsored by the CDC, calls for mandatory HIV antibody testing were rejected as a counterproductive public health measure which may also lead to discrimination.[48]

The issue of testing and subsequent stigmatization is not a new one among minority communities. In 1970, for example, a single, inexpensive and relatively reliable test for sickle cell hemoglobin became available.[49] Shortly thereafter, a number of states enacted sickle cell testing programs. Some were compulsory and none had specific confidentiality protections. Although well-intentioned, these programs and the attention they generated triggered a response of panic and discrimination. There was confusion over the difference between carrying the trait and having the disease. Some airlines grounded all Black employees because of fears that a sickling crisis might occur if a plane de-pressurized; some insurance companies began charging higher premiums for sickle cell carriers; and the armed forces considered deferring enlistment of all carriers.[50]

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[47] See: N. Hunter, "AIDS Prevention and Civil Liberties: The False Security of Mandatory Testing." American Civil Liberties Union, 1987.

[48] Public forum on proposed mandatory HIV antibody testing held in Atlanta, Georgia on February 28, 1987.

[49] Sickle cell anemia is a serious genetic blood disorder which primarily affects black people. It causes severe physical debilitation and often results in death at an early age.

Any policy or program calling for required testing for the HIV antibody test and the subsequent exclusion or segregation in the event of a positive result must be evaluated in terms of its impact on people of color. In October, 1985, the federal government began testing applicants for military service. Since then testing in the military has been expanded to include active duty personnel and their dependents (in some circumstances). Reserve personnel are also being tested. In March, 1987, the Labor Department began testing applicants for the Job Corps. The State Department now tests all applicants for the Foreign Service. The federal government has announced plans to test all prisoners in federal prisons and immigrants.

Significant amounts of unemployment and underemployment among people of color and the soaring cost of higher education in the United States have led many minority youths to use the military and the Job Corps as a means of acquiring training, job skills, and employment.

> All other things being equal, the military's policy will, by necessity, have a discriminatory impact upon poor people of color, given the

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[50] P. Reilly, Genetics, Law and Social Policy (1977) at 74. This paragraph is quoted from N. Hunter, "AIDS Prevention and Civil Liberties: The False Security of Mandatory Testing", American Civil Liberties Union, 1987 at 18.

> number of Black and Hispanic recruits. This disproportionate impact is, of course, further exacerbated by the fact that Black and Hispanic people have been exposed to HIV in far greater proportions than have white people.[51]

The Department of Labor's testing of Job Corps applicants has a similar impact.

> Job Corps is a federally funded job training program for economically disadvantaged persons between the ages of 16 and 21. A large proportion of Job Corps participants are people of color. For most Job Corps members, the program is the last available opportunity to obtain job skills and a realistic expectation of future employment.[52]

Testing of prisoners also produces a disparate impact upon people of color, given the high proportion of minorities who are incarcerated. Wherever there exists a profession or an otherwise identifiable, formally-ordered segment of the population which is made up largely of minorities, mandatory testing of these groups will naturally take a heavy toll among minorities. Thusfar, the great proportion of those groups undergoing such testing do indeed have a high minority representation. A recent article in New York Newsday reported New York City and New Jersey Boxing Commission officials calling for widespread testing and exclusion of those testing HIV antibody positive among boxers.[53] Even forced testing of women arrested for prostitution has a disproportionate impact on minority communities because women of color, while not comprising the majority of sex industry workers, are more likely to be arrested.

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[51] Katherine Franke, "AIDS and Race," The Exchange, National Lawyer's Guild AIDS Network, Issue 4, May, 1987, p.4.

[52] Id.

[53] W. Matthews, "Rubber Gloves for this Fight", New York Newsday, July 26, 1987, Sports 28.

**The NYC Commission on Human Rights' Response**

In response to the discrimination aspect of the AIDS epidemic, the New York City Commission on Human Rights has created an AIDS Discrimination Unit to provide assistance to persons with AIDS, persons assumed to have AIDS, those who test HIV positive and those who are feared because they are or are perceived to be members of an "at-risk" group. The Commission accepts these complaints under the New York City Human Rights Law's prohibition against discrimination on the basis of physical handicap in housing, employment and public accommodations. As of June 30, 1987, the Commission had received over 750 reports of discrimination related to AIDS. Many of these complaints set forth charges of systemic discrimination, for example where a company has a policy of refusing to deliver medical supplies to homebound AIDS patients, or where any employee suspected of having AIDS is immediately terminated. All indications are that AIDS-related discrimination is widespread and growing.[54]

The Commission's AIDS Discrimination Unit has received calls from the families of people with AIDS requesting assistance in their efforts to obtain necessary medical assistance and procedures for a relative with AIDS. AIDS Discrimination Unit staff have arranged for emergency service by ambulance, fought to obtain much-needed medical/dental care, insured access to funeral homes which denied services, and advised delivery personnel of the illegality and monetary repercussions of refusing to furnish services to persons with AIDS or those who associate with persons with AIDS. The Unit has interceded in a wide range of discrimination cases and many times obtained a positive result due to efforts to advocate on behalf of the person with AIDS. More recently the Commission launched an educational campaign to alert the public to the fact that AIDS-related discrimination is illegal and to counter the growing backlash against people with AIDS.

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[54] See: New York City Commission on Human Rights, Updated Report on AIDS Discrimination, August, 1987 for summaries of cases.

## Projections for the Future

It has been estimated by the U.S. Public Health Service that by 1991, 3-4 million Americans will have become infected with HIV - about one in every 70 people. There will be over 270,000 cases of AIDS nationally, resulting in 179,000 deaths.[55] (Studies done in the United States indicate that within a six year period approximately 20-30% of all persons who test HIV positive will go on to develop AIDS and another 20-30% will develop AIDS Related Complex [ARC].) In New York City, AIDS is already the current leading cause of death for males aged 25-44 and for females aged 25-34. It is the third leading cause of death for females aged 35-44.[56] Health officials, charting the progressive course of the disease, have predicted that 43,000 AIDS cases will have been reported within New York City by 1991 and it is likely that 31,000 of these people will have died.[57] **The majority of those who die in this manner will be men, women and children of color.**

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[55] C. Everett Koop, Surgeon General's Report on Acquired Immune Deficiency Syndrome, October, 1986.

The World Health Organization estimates that there will be 500,000 to 3 million new AIDS cases between 1987 and 1991, in people who were already infected with HIV as of 1986. They report that 50 million to 100 million people will be infected with HIV worldwide by 1991.[58]

AIDS is a global problem, a pandemic. The majority of those affected by AIDS and HIV infection are now and will continue to be people of color and the population of the third world. The discrimination and lack of resources which disparately affect the poor and people of color with AIDS in the United States are part of a global pattern of discrimination and lack of resources.[59] As Jonathan Mann, Director of the World Health Organization recently stated:

> Fear and ignorance about AIDS continues to lead to tragedies: personal, family, and social. In some

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[56] Conversation with Dr. Singh, New York City Health Department, July, 1987.

[57] Official projections, New York City Department of Health, July 28, 1987, based on cases diagnosed through December, 1986.

[58] World Health Organization, Special Programme on AIDS, "Strategies and Structure, Projected Needs," March, 1987, p. 18.

[59] See: Panos Dossier 1, AIDS and the Third World. (Revised and Updated Edition),The Panos Institute, March 1987.

> circles, the HIV-infected are still divided by some into the "innocent" and, by implication, the "guilty" persons. Fortunately, other groups, such as the World Council of Churches, have issued eloquent pleas for understanding, for healing, and for compassion.
> ...
>
> Inevitably and necessarily, the social debates about AIDS acquire a distinct political dimension. AIDS has become a touchstone for political beliefs. AIDS has unveiled thinly disguised prejudice about race, religion, social class, and nationality. As a result, we are witnessing a rising wave of stigmatization: against Westerners in Asia, against Africans in Europe, of homosexuals, of prostitutes, of hemophiliacs, of recipients of blood transfusions. AIDS, or more properly fears about AIDS, has become a direct threat to free travel between countries, and, more generally, to open international exchange and communication[60]

## Conclusion

Tremendous strides have been made over the last five years and we now know quite a bit about Acquired Immune Deficiency Syndrome. All the scientific evidence states that AIDS is not spread by casual contact. The National Centers for Disease Control have issued guidelines which clearly state that, except in certain well-defined instances, caring for, or living or working with a person who has AIDS or who is HIV-positive presents no health risk.[61] AIDS is not transmitted by holding hands, sneezing, coughing, or sharing eating utensils or sanitary facilities. We also know how it is spread. AIDS is transmitted through blood-to-blood contact (such as shared needles which have come into contact with HIV-contaminated blood), blood-to-exposed mucous membrane contact (such as contact in a medical setting where the recommended precautions are not followed), semen-to-mucous membrane contact (unsafe sexual practices such as anal and/or vaginal intercourse without a condom with an HIV-infected partner), and from pregnant mother to unborn child.

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[60] Jonathan Mann, "AIDS Epidemiology, Impact, Prevention and Control: The World Health Organization Prespective," paper presented at Third International Conference on AIDS.

[61] See: "Recommendations Regarding HTLV-III Transmission in the Workplace", Morbidity and Mortality Weekly Report, November 15, 1985.

Prejudice against racial and ethnic minorities ("they're all on welfare"), homosexuals ("they're only fags"), immigrants ("they're taking our jobs away"), sexually active women ("she's a whore and deserves what she gets") and drug users ("they're nothing but junkies anyway") interferes with our ability to respond to AIDS as a health crisis. As the wife of one man with AIDS noted, "...the labeling of this disease [into risk group categories] has got to stop. When we're labeled, we're no longer people."[62] This stigmatization of AIDS as "their" disease diverts our attention away from the very real social, economic, discrimination and health issues which affect us all.

Education combined with aggressive enforcement of our civil rights laws is an effective weapon against prejudice and discrimination. Don't let anyone convince you that AIDS is someone else's problem. To support this myth is to assure the continued spread of both the HIV virus and the stigma associated with AIDS, while fueling the growing backlash against women and racial, ethnic and sexual minorities.

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[62] C. Norwood, "AIDS Goes Straight," Us Magazine, August 25, 1986, pp. 47, 49.

Contacts within the AIDS Discrimination Unit:

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Note: Copies of "**NYC Commission on Human Rights Report on Discrimination Against People With AIDS, Update: January 1986 - June 1987**", are available upon request. This report details representative accounts of AIDS and AIDS-related discrimination reported to the Commission, and includes an analysis of the trends and special circumstances surrounding AIDS discrimination.

## APPENDIX: A BRIEF OVERVIEW OF SOME EDUCATIONAL OUTREACH EFFORTS DIRECTED TOWARD MINORITY POPULATIONS WHICH HAVE BEEN UNDERTAKEN BY THE NEW YORK CITY DEPARTMENT OF HEALTH AND THE BOARD OF EDUCATION*:

Because AIDS is still thought to be a white, gay male disease, many people of color don't realize that they are at risk for AIDS. For this reason, many community groups and the New York City Department of Health's AIDS Education Unit have begun outreach efforts in minority communities.

The Department of Health works with many community groups to develop AIDS educational materials. Currently, the Department of Health provides some funding to the Haitian Coalition on AIDS, the Hispanic AIDS Forum, the Minority Task Force on AIDS and the Gay Men's Health Crisis for a variety of educational materials, including brochures in Creole, audiocassettes in Spanish and Creole, and a comic book. The Department of Health sponsors a weekly AIDS educational segment on the Gay Cable Network and has taken out ads in publications of the Hispanic, Black, and Haitian communities. Videos are also being prepared in both Spanish and English to be used in counseling IV drug users.

The City Department of Health's AIDS Education Unit currently has an outreach effort in nine primarily Hispanic and Black communities throughout the boroughs. These particular communities were targeted due to a high incidence of IV drug use. The focus has been to educate both IV drug users and all other community members about AIDS transmission. The AIDS Education

Unit attempts to reach IV drug users and those with whom they interact, including sexual partners, children, and other family members.

These programs have made strides in educating the public about AIDS facts and myths; however many more people need to be reached. Communication methods such as audio/visual educational materials, street theatre and, especially, peer outreach efforts by former addicts are some methods which have been used to good effect as a means by which to educate this group about the risks of HIV transmission. Creative ideas are necessary to reach this segment of the population, which has traditionally been underserved by organized health care and education.

The AIDS Education Unit is aware of the need to educate women about the special situations they face during the epidemic and has undertaken a number of programs designed to meet this need. The unit's emphasis is on reaching the entire community, including women. Women's risk of contracting AIDS from unprotected sexual encounters is discussed in general educational presentations. The unit also does outreach at places where large numbers of women can be reached, such as Head Start centers and WIC offices. The City also has pamphlets entitled "Women and AIDS," and "Children and AIDS." The City's AIDS Hotline conducts groups for women where their questions and concerns can be raised and addressed. Several community groups and agencies have also responded to this need, sponsoring educational forums and producing pamphlets which detail the risks women may face and provide suggestions on how they may protect themselves.

Special outreach efforts are now being directed at children and teenagers. It is presently part of the required curriculum of the New York City public high school system that students be given AIDS Education. A new film that the New York City Board of Education will show in New York City public high schools and some middle schools includes a discussion among five teenagers (three female and two male; several of whom are minority teenagers) about AIDS and risk reduction. The AIDS Education Unit also has a brochure for adolescents about AIDS. The entire brochure, including concept, design and graphics, was designed by adolescents.

The AIDS Education Unit also has a program for inmate education about AIDS in the city's correctional facility on Rikers Island, including the male, female, detoxification, and adolescent facilities, and in city correctional facilities in each borough. Starting August 1987, the AIDS Education Unit began distributing an inmate release packet, including condoms and AIDS education materials, to all released inmates on Rikers Island. And, in a new pilot project, condoms are now being distributed to inmates in the section of Rikers which houses gay men.

The work of the gay community in AIDS education shows the success that grassroots, culturally relevant educational campaigns can achieve. Many gay community groups have developed brochures, videos, comic books and other materials which discuss safer sex guidelines and the special needs of gay men. Studies in New York City and San Francisco have shown that many members of the gay community have significantly changed their sexual behavior to incorporate risk reduction techniques; to a large degree, this behavioral change is a direct result of education. Although the efforts of gay community groups have been very effective in reaching many homosexually active men, still more work is needed to educate those men who are sexually active with other men, without the use of risk reduction-techniques. Educational efforts should emphasize reaching men of color and young and adolescent men. The New York City Department of Health is currently working on a brochure for men who are sexually active with other men.

The Office of Lesbian and Gay Health Concerns of the New York City Department of Health is now doing outreach to gay and bisexual men of color. They are providing education to men in bars, clubs, and on beaches.

In this section, we have only touched upon some of the many legitimate efforts which have been proposed by both City and community organizations to care for and protect the various segments of the public affected by AIDS. These programs need our full support to be implemented.

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* The information in this appendix was provided by the New York City Board of Education and the following divisions within the New York City Department of Health: Division of AIDS Program Services, AIDS Education Unit, and Office of Lesbian and Gay Health Concerns.

The City of New York

THE AIDS DISCRIMINATION UNIT

of the

NEW YORK CITY COMMISSION ON HUMAN RIGHTS

Updated August 20, 1987

# Report on Discrimination Against People with AIDS and People Perceived to have AIDS

January 1986 - June 1987

**Hon. Edward I. Koch**
Mayor

**Dr. Marcella Maxwell**
Chairperson

**Alberta B. Fuentes**
Executive Director

# Report on Discrimination Against People with AIDS and People Perceived to have AIDS

January 1986 - June 1987

## INTRODUCTION

The Human Rights Law of the City of New York prohibits discrimination in the areas of housing, employment and public accommodation on the basis of an individual's handicap or disability. The NYC Commission on Human Rights has taken the position that it has jurisdiction over all complaints of AIDS and AIDS-related discrimination under the protection afforded by the present statutory provisions. Consequently, the NYC Commission on Human Rights accepts complaints from and offers assistance to:

- People with AIDS
- People with ARC (AIDS-Related Complex)
- Those who have tested HIV antibody positive
- Members of a group considered to be at risk for AIDS
- Family members, co-workers, lovers and/or friends of someone in the above four categories who believe they have been discriminated against because of their association with this individual.

The Commission received its first reported incident of AIDS discrimination in June, 1983. Thereafter the AIDS Discrimination Unit was established to document and respond to complaints of AIDS-related discrimination. Our mandate is a broad one -- to eliminate AIDS discrimination. To date, the Commission has received more than 750 reported incidents of AIDS-related discrimination. This report summarizes a representative sample of complaints received by the unit from January, 1986 through June, 1987. Because of the large increase in the number of reported discriminatory incidents, it is impossible to include them all within this report.[1]

## HIV-RELATED DISCRIMINATION

AIDS discrimination differs from other forms of discrimination in that it often occurs in a crisis setting and therefore does not lend itself to the normal legal process. If the oxygen company will not make a delivery, if the hospital bed has not been cleaned in days, or if a dentist will not provide treatment for a person with AIDS, the person affected cannot wait the weeks or months necessary for a complaint to be filed, to be investigated and to proceed to a public hearing. These situations require an immediate response and an expedited problem-solving approach - advocacy - is often our best tool.

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[1] An earlier report, covering the period November 1983-April 1986 contains summaries of the first 170 AIDS-related discrimination complaints received by the Commission. Copies are available upon request.

We often speak of three components of AIDS discrimination: fear, misinformation and prejudice. By identifying which factors are operating in a given situation, we can better address the underlying problem.[2] Part of our role is to assist service providers, community activists and persons with AIDS in identifying incidents of discrimination. And, since most people with AIDS, as well as the people who assist them, are unable, because they are trying to survive or helping someone get needed services, to deal with discrimination, it is the role of the human rights agency to not only remedy the instant situation, but to attempt to eradicate the problem at its core so that it does not reoccur. Wherever possible the Commission attempts to take the burden of AIDS discrimination off the individual's back. Utilizing this systemic approach has proved to be very effective in achieving this goal.

As the AIDS epidemic has spread, so too has the scope of AIDS-related discrimination. Some segments of the public, fearful of AIDS, have labeled and stigmatized "AIDS victims" and singled them out for condemnation, mistreatment and discrimination. There is a growing group of people who do not have AIDS but are nevertheless targeted for AIDS-related discrimination: those who are perceived to be "AIDS risks". This group includes intravenous drug users, homosexuals, prostitutes, Haitians, homeless men and women, the poor, racial and ethnic minorities, people known to have tested positive for HIV antibodies and anyone who loves and cares for people with AIDS. We have found that no one involved in the care or support system of a person with AIDS is immune from adverse public reactions due to the relationship.

## Demographics of AIDS within New York City

AIDS crosses racial, ethnic, national origin, age, gender, class and sexual orientation lines. In New York City, 55% of all persons with AIDS are Black or Hispanic. This figure is greater than the 44% population figure for Blacks and Hispanics living in New York City.[3] Because the percentage of Blacks and Hispanics with AIDS has increased over the last year (it was 53% in 1986), we must assume that Blacks and Hispanics are currently being diagnosed at a much higher rate to effect this overall percentage.

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[2] Fears often have to be acknowledged and examined before information can be imparted. Misinformation is corrected by asking people to explain their positions and then supplying data, printed materials and speakers to educate them. Prejudice must be identified as such, examined and discussed but ultimately rejected as an unacceptable basis for action.

As of June 1987, intravenous drug users constitute 30% of all adult AIDS cases in New York City. (An additional 5% of adult AIDS cases were men who both used intravenous drugs and had unprotected sex with other men.) In part because drug use is subject to criminal prosecution, it has been difficult to establish lines of communication with members of this population.

Gay men of all races continue to be targets of AIDS discrimination. Still, many people continue to believe that all persons with AIDS are white, gay men. In New York City, 35% of the homosexually active men with AIDS are Black or Hispanic. This raises other issues about the effects of homophobia within all communities. But regardless of race, merely "looking gay" may result in assumptions being made about an individual's risk of contracting AIDS and often leads to loss of jobs, housing and access to health care.

AIDS and HIV-related discrimination[4] have had a devastating impact on women's lives in a multitude of ways which extend far beyond medical issues. In our society women often serve as primary caretakers for the sick -- whether as mothers, friends, wives, sisters or health care providers. Many incidents of discrimination were reported by women who do not have AIDS but rather care for or support a person with AIDS.[5] The burden placed on women is tremendous. As caretakers they watch their loved ones endure the pain and humiliation attendant to sickness and discrimination. And if they themselves become HIV antibody positive or contract AIDS, the immediate impact on the extended family can be devastating. Antibody status has even been used as a basis to charge that a woman is an unfit parent.

[3] On the national level, the statistical gap is even wider: while Blacks comprise only 12% of the total population, more than 24% of those with AIDS in the United States are Black. Similarly Hispanics, who comprise only 6% of our national population, represent 14% of all people with AIDS in the United States.

[4] i.e. discrimination which is due to the person's having been diagnosed with AIDS or any other HIV-related disease; or because the person is HIV antibody positive; or because the person is perceived to be any of the above. Note: HIV stands for Human Immunodeficiency Virus, thought to be the cause of AIDS.

[5] In 1986, 20% of the 314 AIDS-related complaints (and in the first six months of 1987 - 21% of the 300) brought to the Commission involved women.

Although present statutory provisions do not include discrimination against people who are incarcerated or under the supervision of the parole or probation system, incidents of human rights violations related to AIDS are increasingly being reported to the Commission from within the criminal justice system. The rate of AIDS among inmates in the NY State Correctional System has jumped from 30+ during 1985 to 80+ during 1987. The Commission documents these reports of discrimination, provides information and educational materials and, where appropriate, contacts corrections authorities in an effort to resolve problems.

Because so many communities are affected by AIDS, a wide variety of issues arise, all of which merit our attention and response. And that response is a continuing foray into a new and compelling area of discrimination law. The Commission joins others who concern themselves with the problems related to this tragic epidemic in summarizing and documenting what our experience has been since 1983.

The incidents related in the body of this report are representative summaries of individual and systemic complaints. By systemic, it is meant that the problem is company- or industry-wide, that a tacit or written policy exists which would adversely affect any person with AIDS or perceived to have AIDS who came into contact with the policy. This type of complaint is common and it is significant in that the number of people adversely affected by the practice may well be much higher than the number of reports received. For every report of systemic discrimination received, we must consider that scores of people with AIDS or those perceived to have AIDS may have been denied services, jobs or housing. By addressing areas of systemic discrimination, the Commission has a major impact against AIDS-related discrimination.

To assist the reader, complaints have been grouped by category -- employment, housing and subdivisions of public accommodations. Seeing these complaints in type-groups furthers an understanding of the similar and recurring nature of the problems. At the beginning of each section there is a brief explanatory statement about the particular problems surrounding each issue.

NOTE: Statistics appear at the end of the report.

## EMPLOYMENT

Because AIDS is construed to be a physical disability, adverse decisions about the hiring, firing, promotion or terms and conditions of someone's employment, if based on an individual's having been diagnosed with AIDS (or the perception that someone has or could develop AIDS), are prohibited under the human rights law.

In the last year, the Commission has observed an encouraging trend among large employers to seriously examine AIDS as a workplace issue. Many personnel officers and law firms representing employers contacted the Commission and requested that the AIDS Discrimination Unit assist them to formulate rational, nondiscriminatory policies regarding AIDS. Despite this trend, employees -- particularly those in jobs with a great amount of client contact (e.g. restaurants, hotels, transportation) -- continued to report AIDS-related discrimination.

Many incidents result in termination. Lack of accurate information about the syndrome often prompts irrational reactions from co-workers and employers alike. Mere mention by a seemingly healthy individual of involvement with someone who has AIDS can lead to the loss of employment. After accepting such complaints, the Commission was often able to assist complainants in obtaining reinstatement or financial settlements. The Centers for Disease Control has determined that no precautions need be taken in most work environments and has issued guidelines accordingly. Increasingly, through education, employers and employees have begun to understand that AIDS is not communicated by casual contact.

Employers, hoping to avoid any disruption of the work environment, often terminate employees with AIDS to pacify frightened staffmembers. It is imperative that all employers be advised that AIDS-related discrimination is against the law. An additional impetus is provided by the reminder of the expense of time and money which may have to be devoted to dealing with a discrimination suit, should an employee with AIDS choose to fight an unlawful termination.

Reports have been received that some insurance companies, reacting to the heavy burden of AIDS-related health care costs, are pressuring employers to determine, prior to hire if they can, the likelihood of a potential employee contracting AIDS. The ELISA Blood Test, which tests for the presence of antibodies to HIV (Human Immunodeficiency Virus, the agent generally thought to cause AIDS) and the back-up Western Blot test, are the methods most commonly used by employers to screen prospective and current employees. The public and the media frequently mistake this as an AIDS test and perpetuate the erroneous assumption that those who test HIV antibody positive have or will soon get AIDS. A positive test result does not mean an individual has or will get AIDS; it indicates exposure to a virus associated with the syndrome. Yet willingness to be subjected to the test is sometimes a pre-condition -- albeit an illegal one -- to employment, thus placing job applicants in a very difficult situation.

The Commission investigates allegations of discriminatory employment practices to determine whether employees with AIDS have been treated differently from other employees. As discriminators become more sophisticated, seemingly neutral policies and decisions must be closely scrutinized to ensure that they are not a subterfuge for discrimination or applied in an arbitrary manner which adversely affects employees who are perceived to have or be at risk for AIDS. Below are several employment discrimination reports:

## EMPLOYMENT DISCRIMINATION CASES

**SEPTEMBER 1985**
**EMPLOYMENT/PERCEIVED AIDS/HIV ANTIBODY TESTING**

A woman from Brooklyn, whose boyfriend had died due to complications caused by AIDS, called with a problem. She had confided in a co-worker the cause of her obvious grief and soon thereafter no one in the office would speak to her. She called because she had just been told by the personnel director that she was being placed on "indefinite leave without pay" until she could "prove" that she doesn't have AIDS. He said he "had to" let her go because two other employees "threatened to quit and sue the company" if she was allowed to remain on the job. She called the Commission only to find out where she could "get the AIDS test." We explained that 1) before she considered taking the test for HIV antibodies, she should be aware of the possible repercussions she might experience if she tested positive, 2) she represented no health risk to co-workers, and wouldn't even if she did have AIDS, and 3) her employer was violating her civil rights and she was entitled to file a complaint with the Commission to rectify the situation.. We offered to speak directly to her employer to explain these facts. Jurisdictional, but no complaint was filed.

**NOVEMBER 1986**
**EMPLOYMENT/TERMINATION/ACTUAL AIDS**

A man who worked as an instructor for a beauty school for a number of years took an authorized sick leave. During that leave he was diagnosed with AIDS. When his health stabilized and he attempted to return to work, the school refused to reinstate him because of an alleged hiring freeze. The man then filed a discrimination complaint with the Commission and the school admitted to the Commission investigator that they refused to permit the man to return to work because of his AIDS condition. Though the man provided documentation from a doctor confirming his ability to work, the school insisted a person with AIDS could not perform the job. The Commission investigation supported the complainant's allegations and a public hearing will be held to resolve the matter.

**MAY 1987**
**EMPLOYMENT/ACTUAL AIDS**

A teacher whose employer did not know he had AIDS had been paying $1,000 per month out of his own limited salary because he felt that he couldn't risk submitting a claim to his insurance company to recover the cost of the life-saving but extremely expensive drug therapy (AZT) he was undergoing. Because the drug is considered AIDS-specific and has been widely mentioned by the media in connection with AIDS, he feared that the insurance company would notify his employer of his illness and he would be terminated. We called his insurance agent and then reported back to the teacher the nature of the confidentiality controls which governed his situation. We also assured him that, if he were terminated because his employer discovered he had AIDS, the Commission would be there to accept, investigate and hopefully remedy his discrimination complaint.

**FEBRUARY 1987**
**EMPLOYMENT/TERMINATION/ACTUAL AIDS**

A man with AIDS worked as a manager for an international airline for many years. When illness required him to take sick leave, the company granted him a one month absence. However, later requests for additional sick time and a reduced work schedule were denied. The man filed a complaint with the Commission, alleging employment discrimination and pointing out that the company permitted managers with non-AIDS-related illnesses to take unlimited sick leave. The Commission negotiated a settlement whereby the Complainant received $12,000 compensation and the employer agreed to continue to pay for the man's health insurance for two years.

**MARCH 1987**
**EMPLOYMENT/TERMINATION/ACTUAL AIDS**

The brother of a woman diagnosed with AIDS called to report that, when his sister's employer visited her at the hospital and learned about her diagnosis, he fired her. The brother said that she worked as a secretary for a small firm of only two employees. The Commission attempted to resolve the situation through advocacy but was not successful. Due to a lack of jurisdiction over employers which have fewer than three employees, we were unable to accept a formal complaint from the woman.

**MAY 1987**
**EMPLOYMENT/HIV ANTIBODY TESTING**

An advertising executive called the Commission to ask if potential employers can require that applicants take the HIV antibody blood test. We told him that this is an illegal requirement and advised him that he could file a complaint if he was denied employment for which he was otherwise qualified because of a positive result or due to his refusal to take the test. He would not divulge the name of the company, but informed us that it is a large advertising firm. The job he was applying for was "very high level" and he felt he couldn't refuse to take the test nor could he file a complaint because the advertising industry is "a small town" and everyone in the business would know that he'd "gone outside." He felt his advertising career would be over if this occurred and so he decided to take the test. We did not hear from him again.

**JUNE 1987**
**EMPLOYMENT/VERBAL HARASSMENT/PERCEIVED AIDS**

A gay male government employee called to say that he held the elevator door open for a female co-worker who thanked him and then commented to a male co-worker that the gay man had acted "like a gentleman." The male co-worker responded that where he comes from, they "don't call them gentlemen," that such "gentlemen use their charms to give everyone AIDS." The Commission alerted the co-worker's supervisor, who then met with both men. The co-worker apologized to the complainant for his offensive remark and the supervisor informed the co-worker that discriminatory remarks would not be tolerated by management.

**APRIL 1987**
**EMPLOYMENT/TERMINATION/PERCEIVED AIDS/HIV ANTIBODY TESTING/CONFIDENTIALITY**

A woman who worked as an intensive care unit nurse at a private hospital for six years was contemplating becoming pregnant and, for this reason, requested the HIV test offered by her employer. She first queried the administration about guarantees of confidentiality regarding the test result and was assured that the result would be "absolutely confidential." When she tested positive, confidentiality was immediately violated. The hospital first told her she had the choice of accepting reassignment to an area not in her field of expertise or resigning and accepting one month's severance pay. The Commission accepted her complaint and, after investigating the matter, found that the Complainant had indeed been discriminated against. If the situation cannot be resolved, a public hearing will be held on the matter.

**MAY 1987**

**EMPLOYMENT/PUBLIC ACCOMMODATION/HIV ANTIBODY TEST/CONFIDENTIALITY**

A supervisor at one of the city's anonymous HIV test sites called the Commission because he was taken aback by the volume of mandatory test requests being presented by clients. He had noted a large number of people presenting letters from dentists, the Peace Corps and other potential employers, directing them to take the HIV antibody blood test with negative results as a requirement for treatment or employment. He said the people indicated little or no knowledge of the import of the test; they only knew that they wanted to be treated by their dentist, keep their job, etc. We advised our caller to inform people in this situation of their right to file a complaint with the Commission if, due to a positive test result or a refusal to take the test, they are denied a job or services. In addition, he agreed to leave the Commission's "AIDS-Related Discrimination Is Illegal" flyers and brochures in the reception area of the clinic.

**JANUARY 1985**
**PROSTITUTES/BIAS/VIOLENCE/PERCEIVED AIDS**

A church worker who deals with prostitutes in the course of her work called the Commission to express concern about the AIDS backlash she sees affecting prostitutes - particularly streetworkers, who are vunerable to attack in their open environment. She reported an increase in arrests, harassment and violence towards prostitutes. No jurisdiction.

## HOUSING

Some of the most devastating discrimination reports brought to the Commission involve housing. In such cases, not only does the person with AIDS have to cope with a swift decline in health but the individual also must face the possibility of having nowhere to live during this crisis. Landlords have been charged with refusing to make repairs or provide essential services, interrupting heat and hot water (vital issues when one is well; life-threatening factors for those in poor health) and harassing people with AIDS in an attempt to illegally evict them from their apartments. Misinformation about the syndrome, often compounded by pre-existing biases about gay men, IV drug users, immigrants or any other group connected by popular opinion to AIDS, may generate the irrational fears which underlie every discriminatory incident.

The spectre of discrimination does not stop with the person with AIDS. Life partners of people with AIDS have had to battle landlords in the courts to preserve their right to remain in an apartment after the named tenant with AIDS dies. It is often difficult in such situations to separate the landlord's desire to reap the economic benefit of a vacant apartment from specific AIDS fears which may be present. But at times, it is clear that the landlord, in an opportunistic stroke, utilizes AIDS panic to his or her financial gain.

The Commission has also received complaints of discrimination in the rental of commercial space. Organizations which provide services to people with AIDS have been denied leases or have been pressured by landlords to limit the access of people with AIDS. Medical professionals (doctors, dentists and laboratories) have also reported termination of their leases or refusal to rent when it becomes known that their patients include persons with AIDS. Several housing discrimination case summaries follow:

## HOUSING CASES:

**OCTOBER 1984**
**HOUSING/ACTUAL AIDS**

The wife of a man with AIDS called to say that her heat and hot water had been turned off by her landlord in an effort to drive the family out, due to his fear of AIDS. She only wanted the services restored and did not have the time to devote to a discrimination complaint. We made several phone calls, suggested referrals and the situation was resolved.

**APRIL 1986**
**HOUSING/ACTUAL AIDS**

A young dentist initiating a private practice subleased office space from a senior, established practitioner. After working together successfully for the first months, the senior dentist learned that the younger dentist was treating patients with AIDS and had agreed to having his name placed on a professional services referral list for people with AIDS-related conditions. The senior dentist insisted the younger dentist cease treating AIDS patients and remove his name from the referral list. When the younger dentist announced his intention to continue to offer his services to the AIDS-affected community, the senior dentist terminated the sublease. The younger dentist filed a complaint with the Commission, a public hearing was held on the matter and all parties are now awaiting a decision.

**JANUARY 1987**
**HOUSING/PERCEIVED AIDS**

An organization attempting to establish a national AIDS hotline signed a lease with a realty company for the rental of office space. Prior to the date of occupancy, the company denied the hotline organization keys to the space, explaining that other tenants objected to the presence of an AIDS-related group. There was apparently a fear that people with AIDS might work in the office space. The AIDS hotline organization filed a complaint with the Commission. A speedy investigation ensued, probable cause was found to credit the allegations of the complaint, and the space was "posted" by the Commission (a process whereby the space is officially removed from the marketplace until the matter is resolved) all within approximately 24 hours of the filing of the complaint. Given the impetus of this process, the AIDS hotline director found he was then able to negotiate with the landlord to successfully obtain suitable office space.

### MAY 1987
### HOUSING/ACTUAL AIDS

A man with AIDS, who lived in a Manhattan residential building which had at least three other tenants with AIDS, was suddenly subjected to many offensive tactics allegedly perpetrated by the owner, superintendant and handyman, all of whom had recently begun to occupy space in the building. During the winter months, the landlord repeatedly left the building on weekends, first shutting off the heat and locking the entrance to the boiler room. On other occasions the handyman assaulted and threatened two tenants in the building, referring to each of them as "a faggot who has AIDS." The Commission accepted a complaint from the man with AIDS, found probable cause, and is attempting to resolve the matter before proceeding with the scheduled hearing.

## PUBLIC ACCOMMODATIONS

The term "public accommodations" as defined in the New York City Administrative Code, includes all establishments which provide goods and services to the public. Because owners and directors of these places of public accommodation are subject to the whims and prejudices of their clientele, there have been a large number of reported incidents where persons with AIDS were excluded from or denied access to a place or service. Often the explanation offered is that staffmembers threatened to quit or that business might decline if a person with AIDS was given access. The law forbids this discriminatory practice and the Commission has acted accordingly.

Many respondents, when faced with a complaint of AIDS-related discrimination, have tried to challenge the Commission's jurisdiction to accept and investigate these complaints. It is indicative of the fear and concern about AIDS which permeate the public arena. As a society we must resist succumbing to misinformed panic. As a human rights agency, it is imperative that a clear message be repeated to all: **AIDS-Related Discrimination is Illegal and Will Not Be Tolerated.**

## DISCRIMINATION IN PUBLIC ACCOMMODATIONS

This section is broken into subcategories, because the term "Public Accommodations" includes not only public places, but services available to the public, including health-related services. Naturally, people with AIDS must seek a wide variety of health-related services and they experience discrimination in this pursuit. For convenience, the section is broken into: dentists and dental clinics; hospitals; health clinics; drug treatment facilities; and other health-related facilities or services.

### DENTISTS AND DENTAL CLINICS:

As of the date this report is being issued, the Commission has accepted 25 complaints of discrimination against private dentists and dental clinics. Several other dental complaints were settled without resorting to the formal complaint process. This is a compelling arena of discrimination because of both the widespread denial of dental services faced by people with AIDS and the urgent need for such services. Because people with AIDS suffer immune deficiencies of varying severity, a simple infection can, if untreated, develop into a life-threatening crisis. The Commission has settled complaints; reversed the discriminatory policies of several dental practices; obtained treatment and/or monetary compensation for complainants; responded to a jurisdictional challenge posed by a leading NYC dental society; and, through active pursuit of all the foregoing, has brought the debate into the public arena. The result of focusing attention on the problem has been a series of meetings between dental societies in the New York area, the NYC Department of Health and the Commission. A helpful, constructive dialogue has ensued and the ripple effect from this exchange may well have a positive effect on the national level. Representative dental complaints have been included in this report to indicate the scope of this problem:

**MARCH 1987**
**DENTIST/DENIAL OF SERVICES/ACTUAL AIDS**

A man with AIDS saw a dentist in private practice to arrange for necessary dental care. During the course of the visit he voluntarily informed the doctor that he had AIDS. The doctor completed the examination, took X-rays, suggested a referral for root canal work and accepted payment for services. However, after the man left his office, the dentist sent him a letter returning both check and X-rays and explaining that his office could not treat people with AIDS. The doctor claimed he could not properly sterilize his instruments and noted that the American Dental Association, the Centers for Disease Control and the New York State Department of Health have issued guidelines recommending adequate and necessary sterilization techniques for all patients for all viruses (including hepatitis and AIDS). The Commission accepted a complaint from the man with AIDS. The dentist, through his professional affiliation, has challenged the Commission's jurisdiction over private practice dentists and this issue is currently before an administrative law judge for determination.

**OCTOBER 86**
**DENTAL CLINIC/DENIAL OF SERVICES/ACTUAL AIDS**

A man who belongs to an employee's union arranged to receive dental care from the union's dental clinic. He voluntarily informed the clinic of his AIDS diagnosis. The dentist refused to treat the man, explaining that their policy prohibited serving people with AIDS at the clinic. Instead such clients were referred to a hospital dental clinic for treatment. The man filed a discrimination complaint which challenges both the legal and scientific basis for this policy. The Commission has accepted and is attempting to resolve complaints from this man and two other members of the union who related similar experiences. A formal hearing is scheduled on these complaints.

**JAN-JUNE 1987**
**PRIVATE DENTAL CLINIC/ACTUAL AIDS**

Many reports were received at the Commission that a chain of private dental clinics in New York City had a firm policy of refusing to treat anyone with AIDS. A Commission investigator called the clinic, ostensibly to arrange an appointment. Once a treatment date had been scheduled, the investigator said that he had AIDS. The receptionist apologized and said that, in that case, the clinic would not treat him. No referral was offered until the investigator pressed the clinic agent for some suggestion as to where he might obtain treatment. The Commission has accepted two individual complaints against this clinic; both were resolved to the satisfaction of the complainant. The Commission is now planning to place test calls to the clinic to see if the policy has altered and, if not, Commission-initiated complaints will be filed against the entire chain.

**FUNERAL HOMES**
**The Systemic Approach to Investigation**

During the period covered by this report, the Commission's AIDS Discrimination Unit regularly attempted to settle individual complaints of funeral home discrimination on a case-by-case basis. Then in July of 1986 the Commission charged three funeral homes with AIDS discrimination. These charges were not filed by an individual complainant but by the Commission itself. They were based on GMHC's (Gay Men's Health Crisis') reports of widespread discrimination against people with AIDS by the funeral homes. The funeral homes were charged with maintaining an alternate, higher price structure for services when the death was AIDS-related; insisting on unnecessary and costly funerary appurtenances (e.g. special seals and casket covers); refusal to embalm; or outright refusal to deal with the body in question.

One of the homes charged challenged the Commission's jurisdiction in court. The resulting court decision supported the Commission's jurisdiction to investigate such complaints. It further clarified three points: 1) that funeral homes are covered in the law's prohibition against discrimination in the area of "public accommodation;" 2) that people have rights not only in life, but also in death, and are entitled to be treated with dignity in both states; and 3) that family members and life partners may file complaints of AIDS discrimination on behalf of the deceased, despite the fact that they themselves do not have AIDS.

As a result of this decision and the continuing efforts of the Commission, concerned community groups and certain leaders within the funeral industry, this problem has been sharply curtailed, though not completely eradicated. As part of our response to this type of discrimination, Commission representatives met with representatives of funeral directors' associations and participated in large educational forums for one association's membership.

In 1987, the Commission again utilized this process and charged an additional five funeral homes with discrimination. Of the eight Commission-initiated complaints which were filed during 1986/87, five have been settled. Each of those funeral homes agreed to alter their policies to conform to the law. The three remaining cases are either under investigation or in the process of conciliation. Two funeral home discrimination case summaries are listed below:

FUNERAL HOME CASES:

**JULY 1986**
**FUNERAL HOME/ACTUAL AIDS/PUBLIC ACCOMMODATION**

The mother of a man who had recently died due to AIDS-related complications called to report that a funeral home in Queens charged her several hundred dollars extra for embalming her son's body and also required her to purchase a "special kit" that was totally unnecessary. We contacted the director of the funeral home and the extra charges were dropped. He also agreed to alter the funeral home's policy to deal in an equitable manner with the bodies of those who die due to AIDS complications.

**AUGUST 1986**
**FUNERAL HOME/ACTUAL AIDS/PUBLIC ACCOMMODATION**

A woman whose seven year old son had died due to AIDS-related complications called. She had been unable to find a funeral home that would provide both embalming and viewing services. She had finally found one funeral home which agreed to allow viewing, but they required that the mother purchase an unnecessary glass casket cover which cost an extra $500. We contacted the funeral director and reminded him of the Commission's agreement with the funeral association of which he was a member - that full services, including embalming and open casket viewing, would be provided to the families and friends of people who have died due to AIDS-related complications at no additional cost, unless additional costs were incurred by the funeral home. The situation was resolved.

## HEALTH CARE FACILITIES

Unlike the large number of allegations of employment discrimination based upon the perception of AIDS in a healthy individual, the majority of reports alleging discrimination by health-related public accommodations such as hospitals and clinics are, naturally, from people who actually have AIDS. Many of the systemic reports involve service providers and life-threatening situations; there can be very serious consequences to discriminating against a person with AIDS.

Doctors, dentists, ambulance drivers, hospital cleaning and food preparation staff, laboratory technicians and therapists have reportedly refused to deal with AIDS patients who require their services. The range of rejections by service providers extends to nursing homes, most of which categorically deny access to patients with AIDS. Here the social worker rather than the patient with AIDS usually has direct knowledge of the discrimination and it is this individual who contacts us. The scope of service rejections is devastating.

### HOSPITALS:

A large number of reports of AIDS discrimination emanate from the hospital setting. Because the individual is usually still a patient within the hospital when the report is received and is thus continuing to experience the problem, the Commission's usual route is to call the hospital's patient representative or another appropriate administrator to see if the difficulty can be remedied without resorting to a formal complaint. This process has proven very successful and most complaints are resolved within 24-48 hours. On other occasions, the family of a person who has died of AIDS-related complications chooses to file a complaint of abusive treatment by a hospital after the event. In such cases, there is the luxury of time and thus a full investigation can be conducted. A few examples of the types of hospital complaints the Commission received are listed below:

## HOSPITAL CASES:

**APRIL 1987**
**HOSPITAL/ACTUAL AIDS**

The mother of a young blind man with AIDS (who has since died) stated that he was subjected to judgemental and moralistic treatment during a stay at a public hospital. During the emergency room intake procedure, doctors embarrassed him with inappropriate questions about his sexuality and specific queries regarding the sexual practices in which he engaged. This questioning delayed the delivery of necessary care. When he refused to answer these questions, staff repeatedly threatened, "You don't want to die, do you?" During his subsequent hospital stay, nurses regularly refused to change his bed sheets, provide him with a bedpan, serve him meals or give him a blanket at night. The hospital also, the mother charged, failed to supply a companion for him, as would be their usual practice were it not for the AIDS diagnosis. Many staff members also openly expressed antipathy towards patients with AIDS. The mother filed a complaint and the Commission is investigating the matter, while also meeting with hospital representatives to ensure that non-discriminatory policies are definitely in place at this time.

**DECEMBER 1986**
**HOSPITAL/DIALYSIS REFUSAL/ACTUAL AIDS**

A social worker whose client had been diagnosed with AIDS and was in immediate need of dialysis called to report that her client was being referred back and forth between two hospitals. Both refused to provide him with dialysis, alleging that they had no available beds. The Commission was able to resolve the situation when, after several phone calls from a Commission advocate, one of the hospitals agreed to provide the man with immediate dialysis.

**APRIL 87**
**DOCTOR/HOSPITAL/REFUSAL OF TREATMENT/PERCEIVED AIDS**

A gay man in need of medical care visited a physician whom he located through a listing supplied by his health plan. While responding to the doctor's inquiries regarding his medical history, the man said he was gay and added that he did not have AIDS. The doctor skeptically questioned the man's assessment of his health status and refused to perform the required procedure, instead referring him to a specialist at a hospital. The specialist, allegedly acting in accordance with hospital policy, refused treatment and made a referral to another facility - again specifically because of the man's sexual orientation. The original doctor and the specialist informed the Commission that "health concerns" justified their automatic referral of any gay patient, regardless of AIDS or HIV antibody status, to outside facilities. The man filed a complaint with the Commission and the matter is presently under investigation.

**APRIL 87**
**HOSPITAL/DISCRIMINATORY TREATMENT/ACTUAL AIDS/CHILD**

An eight year-old girl with AIDS was admitted to a public hospital and was subjected to abusive treatment during her stay. The staff prohibited her from using the common bathroom; nurses would not serve her meals and instead left trays in the hallway; her wheelchair was labelled in an offensive manner; and one nurse threatened, "If you don't stay in your room, I will tie you to your bed." The Commission accepted a complaint from the child's mother and was investigating the matter when the child died. The mother has expressed her continuing interest in pursuing the matter in the hope that "this won't have to happen to another child." The investigation will therefore continue.

**JUNE 87**
**HOSPITAL BARBER/DENIAL OF SERVICES/ACTUAL AIDS/SYSTEMIC**

The lover of a man hospitalized with AIDS called to report that the hospital barber refused to give patients diagnosed with AIDS haircuts because of the nature of their illness. After the Commission contacted the hospital administration, another barber who is willing to provide hair-cutting services to all patients regardless of illness or disability was hired. Jurisdictional; no formal written complaint filed.

OTHER CLINICS:

**MAY 1987**

**CLINIC/FRAUD/PERCEIVED AIDS**

A man with ARC called the Commission. He had responded to a clinic's advertisement which appeared in a gay publication. The ad stated that the clinic specialized in dealing with venereal warts. The man used the clinic's services, informing them that he had been recently diagnosed with ARC. He said the operation he then underwent at the clinic was "botched" and he ended up having to spend a month in bed. Insurance bills then came in, listing a price much greater than that quoted to him by the clinic. The caller said he suspects the clinic preys on gay men, knowing that many are in no position to question an inflated bill, since they fear the insurance company might find out they are gay, HIV positive, or have ARC or AIDS. We referred the caller to the Consumer Fraud Unit of the Attorney General's office.

**JUNE 1987**
**CLINIC/ DENIAL OF SERVICES/PERCEIVED AIDS**

A gay man called to report that when he visited a private medical clinic, he was told by the attending nurse that because of the AIDS epidemic, any patient suspected of having a sexually transmitted disease was required to be treated only at a city (public) clinic. The man left the clinic and paid extra money to be treated elsewhere. The Commission intervened and as a result the clinic reimbursed his expenses, sent him a letter of apology and changed its policy so that all patients will receive prompt attention at this facility.

## DRUG TREATMENT FACILITIES

Because of the connection between intravenous drug use and AIDS, both active and recovering intravenous drug users are experiencing discrimination. Reports have been filed with the Commission that certain drug treatment facilities require HIV testing before admission, and that others eject those suspected of having AIDS or ARC or being HIV-positive. Residents of drug treatment facilities and persons who are registered with out-patient methadone clinics have complained of discrimination experienced in the neighborhood of the facility. And former intravenous drug users have experienced difficulty obtaining medical services after admitting to past IV drug use.

**MARCH 1987**
**PUBLIC ACCOMMODATIONS/RECOVERING DRUG USERS/PERCEIVED AIDS**

The director of a live-in, drug-free treatment program called to say that the residents experienced difficulties obtaining services in the neighborhood immediately surrounding the residence. He said there was a strong perception among neighborhood merchants that the facility's residents were "AIDS carriers" because they had been intravenous drug users. For this reason, residents had been denied entrance to various stores. We advised him of the illegality of this practice and suggested he direct residents to the Commission when this next happened.

**JANUARY 1987**
**DRUG REHABILITATION PROGRAM/DENIAL OF SERVICES/PERCEIVED AIDS/HIV**

A woman called to say that she was dismissed from a rehabilitation program located in Harlem because the director of the program found out that she is HIV antibody positive. The Commission was able to call program officials and resolve the situation by providing AIDS education for the director of the program and helping him to formulate a non-discriminatory policy regarding clients who are known to be HIV positive or who have been diagnosed with AIDS or ARC. The caller was readmitted to the program.

**MAY 1987**
**METHADONE CLINIC/DENIAL OF SERVICES/PERCEIVED AIDS/SYSTEMIC**

A Physician's Assistant working with substance abusers at a city hospital called the Commission to report that a methadone clinic with which the hospital dealt terminated a number of patients who, because the patients exhibited candidiasis (or another opportunistic disease associated with AIDS) were perceived to have AIDS. She said this was a regular occurrence but patients wouldn't take action against the clinic because they feared reprisal. We advised her of the protection afforded complainants under the law, and she recently referred an aggrieved individual, from whom the Commission took a complaint. That matter is presently under investigation.

**JUNE 1987**
**DRUG REHABILITATION CENTER/PERCEIVED AIDS**

The administrator of a live-in drug rehabilitation center ejected a man who had been successfully recovering from his addiction after participating for two months in the program. They perceived him to have AIDS and openly told him that this was the reason for forcing him out of the center. He was not provided with any referrals to other facilities and, having no resources of his own, necessarily relocated to a men's shelter. He filed a complaint and the Commission is now investigating the matter.

OTHER PUBLIC ACCOMMODATIONS

**APRIL 1987**
**ABORTION CLINIC/DENIAL OF SERVICES/HIV STATUS**

A woman called the Commission because she had been ejected from a Bronx abortion clinic when, during a regularly scheduled appointment, she informed the clinic staff that she is HIV-positive. She said they just told her to "get out." We urged the woman to come in and file a complaint but she did not do so, nor did she reveal her own name or the name of the clinic. We were thus precluded from further action.

**NOVEMBER 86**
**RESIDENCE FACILITY/ARC**

The Commission was contacted by the parents of a 17 year old severely retarded girl who had been living for some time in a residence specializing in the care of the severely retarded. She was sent to a local hospital for some tests and while in the hospital she was diagnosed with ARC. The home where she had been living contacted the mother and stated that they would not take her daughter back. Their primary reason for this decision was that the staff were afraid of AIDS. The Commission offered to file a formal complaint if necessary but suggested to the parents and the staff of the residence that a problem-solving approach might work best. The family met again with the director of the home and suggested education for the staff as one solution. After many conversations with the administrators of the residence, the Commission arranged for the facility to be visited by a member of the AIDS Education Unit of the city's Department of Health. A session was held wherein the fears and questions of staff were raised and addressed. This approach worked and the situation was resolved.

**MARCH 1987**
**POSTAL SERVICE/ACTUAL AIDS**

A major postal/delivery service refused to pick up packages from or deliver packages to a residence facility because it housed people with AIDS. The director of the residence filed a complaint on behalf of the residents and the Commission worked with all parties to arrange an amicable settlement through arranging AIDS education for the delivery service staff and designating a contact person within the organization who will deal with any future difficulties.

**JANUARY 1987**
**SOCIAL SERVICES/ARC**

A woman diagnosed with ARC had been trying to meet with her social worker for over a month when finally she called the

Commission to complain. She stated that every time she had a scheduled appointment, the social worker called and cancelled the meeting. The caller also alleged that the last time she was to speak with the social worker she was asked to wait outside the building and was finally interviewed by the director of the Center who told her that the social worker did not want to deal with someone who had been diagnosed with ARC. We referred the woman to the Crisis Intervention Unit of the city's Human Resources Administration, a unit which deals with the service problems of people who have AIDS or ARC.

**NOVEMBER 1986**
**AIDS/PUBLIC ACCOMMODATION/UTILITIES/HOSPITAL SETTING**

A doctor called from Harlem Hospital because a telephone installer flatly refused to install phones in the rooms of AIDS patients. This individual was the foreman of the work-crew assigned to the hospital and thus none of the workers would agree to perform this service. As a result, at least two patients with AIDS did not have telephones. Through advocacy the Commission was able to resolve the situation and insure that the telephones were connected. To date, there have been no more complaints from Harlem Hospital regarding this issue.

**MAY 1987**
**RETAIL STORE/PERCEIVED AIDS**

The owner of a sportswear store prohibited a gay male customer from trying on a pair of pants he was considering purchasing. He was told by the store's owner that he would have to buy them without trying them on. The salesperson further refused to allow the man to return or exchange the pants if he decided to buy them, explaining that the clothing would be "contaminated with AIDS." When the customer protested that AIDS is not transmitted via clothing, the salesperson replied that other customers might not know this and might therefore become alarmed. The man filed a complaint and the Commission is investigating these allegations.

## A NOTE ABOUT INSURANCE:

The Human Rights Law does not specifically exclude insurance from its definition of "public accommodation." However, the Commission's Legal Department is reviewing case law to determine if we are precluded from accepting complaints against insurance companies. Meanwhile, the Commission is keeping a record of reported incidents of discrimination by insurance companies in order to document the problem. Complaints have been made against insurance companies for their refusal to cover treatment costs for people who have AIDS, their arbitrary termination of insurance coverage and their repeated contention that AIDS constitutes a pre-existing condition and is therefore a valid basis upon which to cancel a policy. This has been reported even when an AIDS diagnosis occurs well beyond the end of a waiting period and although the patient had no prior knowledge of his condition. The New York State Commissioner of Insurance has issued a regulation prohibiting use of the HIV antibody test for determining eligibility for health insurance in New York State. The insurance industry has indicated that it will go to court to challenge this regulation.

### CHILDREN:

A number of AIDS and AIDS-related discrimination cases involving children have been brought to the Commission. In 1986, 7% of all cases, (and in the first six months of 1986 2% of all cases) were brought on behalf of children. A sample of those cases follows:

**JUNE 1987**
**CHILD/PERCEIVED AIDS/HIV TEST**

The father of a three year old girl called because he had been contacted by the local office of a child welfare agency. As part of their investigation, he and his daughter (who were both on Medicaid) were ordered to take the HIV antibody test. This request was made because the office found out that his deceased wife was suspected of being HIV-positive. When he objected, he was told that this was in the best interests of the child and that the agency would remove the child if he refused to comply. Through advocacy, the Commission was able to halt the test request. It was then established that the agency's formal policy stated that HIV testing could not be required. In fact, such requests were supposed to be discouraged except where medically necessary. The test request was withdrawn and the agency has plans to clarify its policy on the issue and educate its personnel.

**APRIL 1985**
**SCHOOL/PERCEIVED AIDS/CHILDREN**

A female social worker, whose caseload included a man with AIDS, called to report that two of the man's three stepchildren (all of whom were stated to be "in excellent health") were being kept out of public school. One of the children, an eleven year old, attended a school where the officials discovered that her stepfather has AIDS; they immediately sent her home. The parents were told that she wouldn't be allowed to return because they "can't guarantee the safety of the rest of the children." To make matters worse, an official of the school called the officials of a school which another sibling attended (a ten year old) and alerted them to the health status of the stepfather. The officials at the second school then decided to bar that child from attending. A doctor who is part of the AIDS team which works with the stepfather wrote the schools to state that there is no reason why the children should not be allowed to attend school. We suggested that all parties contact the AIDS Education Unit of the NYC Department of Health. The social worker informed us that an AIDS Education speaker went to both schools to calm their fears and as a result the children are now back in school.

**SEPTEMBER 1986**
**SCHOOL/PERCEIVED AIDS/HIV/CHILDREN**

A woman whose sister recently died of AIDS-related causes called because her sister's sons were directed by the headmaster of their school to take the HIV antibody blood test or not be allowed to return to school. The headmaster was contacted by the Commission and the situation was resolved.

**OCTOBER 1986**
**SCHOOL/CHILDREN/PERCEIVED AIDS**

A private school expelled a young child after learning that her aunt, with whom the child lived, had AIDS. The school first insisted the child receive a medical checkup, and then, fearing the loss of enrollment if others found out, unequivocally refused the child admission. The child's mother filed a complaint and the Commission found there was probable cause to credit the allegations of the complaint. The Commission will present the complainant's case at a public hearing in September, 1987.

PRISON, COURT AND PAROLE SYSTEM:

As mentioned earlier, a number of reports of AIDS and AIDS-related discrimination emanate from the justice setting. In 1986, 3% of all cases and in 1987, 17% of all cases involved the prison, court or parole/probation systems. Sample reports follow:

**JUNE 1987**
**PRISON/COURT/HIV ANTIBODY TEST**

A prisoner in a Westchester County facility had blood drawn for a hepatitis test. Without his consent, his blood was tested for HIV. Before the results were even known, his file was stamped "BEWARE BODY FLUIDS." When his court date came up, the prison guards refused to transport him to the courthouse. When the Judge asked why they wouldn't transport the man, the guards announced, in open court, that it was because "he has AIDS". A newspaper reporter was present at the time and ran a story on the incident, naming the prisoner and stating that he had AIDS. Eventually, because transportation could not be arranged and also because of the fears of court officers, the Judge held the hearing at the prison. The blood test results then came back - negative for HIV antibodies. The newspaper had since run a retraction of their story. No jurisdiction.

**DECEMBER 1986**
**NYC PRISON/COURT/TRANSPORTATION/ACTUAL AIDS**

A detainee at Rikers Island called the Commission to report that, because he has AIDS, his court dates were needlessly postponed or cancelled. As a result, he stated, his incarceration has been unnecessarily prolonged. He said that when he had recently been brought to Criminal Court in Brooklyn, he was left waiting in handcuffs in a cold truck outside the courthouse for over three hours. At the end of three hours, a corrections officer merely authorized his return to prison, without providing a reason for the delay. The next two times he was scheduled for court proceedings, corrections officials claimed they had not received notices from the judge ordering him before the court and therefore refused to transport him. The Commission, lacking jurisdiction to formally investigate these and similar matters, reported the allegations to the Office of Grievance Programs at the New York City Department of Corrections.

**JUNE 1987**
**HIV/CONFIDENTIALITY/COURT SYSTEM**

A woman called the Commission because she had been charged with assault. During the court session to hear the case, the person she allegedly assaulted stated that she had bitten him. He said that, if she would consent to take the HIV antibody test - and if she tested negative, he would drop the charges. The woman called because she had since gone to an anonymous test site and tested HIV positive. She didn't know what to do. We told her that the Commission doesn't have jurisdiction over the court system but, since no one had contracted AIDS from a bite, she should direct her lawyer to argue that the test is inappropriate. We contacted a lawyer who had successfully defended a woman from similar charges and arranged that he would speak to our caller's lawyer.

**JUNE 1987**
**HIV TESTING/PAROLE SYSTEM**

A counselor from an anonymous HIV test site called to report that three people came to the site requesting to be tested because their parole officers ordered them to do so. We arranged for AIDS education to be provided to the parole officers and alerted parole system administrators of the need to further educate their staff.

**MARCH 1987**
**NYS PAROLE/HIV ANTIBODY TEST/PERCEIVED AIDS**

A man who was recently released from a correctional facility called the Commission to report that his parole officer had ordered him to take the HIV antibody test to determine if he has AIDS. The Commission contacted the parole officer and the New York State Division of Parole, provided both with appropriate AIDS education and resolved the situation. The man did not have to take the test.

**APRIL 1987**
**NYC PRISON/PHYSICAL VIOLENCE/ACTUAL AIDS**

A detainee at Rikers Island called the Commission to report an incident of AIDS-related discrimination. While transporting a prisoner with AIDS to Bellevue Hospital to receive AZT treatment, a corrections officer commented: "You can take all the drugs in the world; you're all going to die." The caller alleged that the officer then hit the prisoner in the face with handcuffs and kicked him in the stomach. The prisoner required emergency room care including stitches on his face. The Commission reported these incidents to officials at the New York City Department of Corrections and the matter is being investigated.

## BIAS & VIOLENCE:

This report touches briefly on the widespread problem of bias and violence directed towards those who have or are perceived to have AIDS. People with AIDS have been mortally attacked (and in one case set on fire) in their hospital beds; landlords have physically attacked tenants who have AIDS with lead pipes and knives in an effort to drive them from their homes; a residence for children, some of whom were thought to have AIDS, was burned to the ground before it could open its doors; and scores of reports have been received from gay men who, simply because they presented an exposed target on the street, were violently attacked by sociopaths who shouted anti-AIDS as well as anti-gay epithets throughout the assaults. Recognizing that AIDS stigma has become an issue affecting the stability of whole communities, the Commission's Bias Response Team works together with community groups (for example the NYC Gay and Lesbian Anti-Violence Project or a coalition of community boards in an area hard hit by AIDS) and the New York Police Department to monitor and investigate these incidents. It can only be hoped that, through continuing education, the attitudes which foster such attacks can be diminished. Bias/violence reports follow:

### JUNE 1987
### COMMERCIAL SPACE/PERCEIVED AIDS/BIAS

An AIDS information and referral center was established in the Richmond Hill area of Queens, New York. The group had located and leased commercial space and was engaged in their day-to-day operations when they experienced AIDS backlash firsthand. Although welcomed by some segments of the community, a coalition was formed by the Richmond Hill Block Association, the Richmond Hill Development Corporation and one state assemblyman to drive the center out of the space they legally occupied. This coalition attempted to pressure the landlord to break the AIDS Center's lease. An article appeared in New York Newsday, quoting the coalition as saying the Center posed "a risk to the community." The Commission assisted the Center in their effort to retain the commercial space they had leased and the field offices of the Comission continue to investigate the bias aspect of the situation.

### AUGUST 1986
### BIAS/VIOLENCE/PERCEIVED AIDS

Two groups of gay men were attacked in two separate instances on the same night, apparently by the same group of five golf club-wielding white men. (One of the gay groups was made up of three Hispanic teenagers; the other of two white men.) The gay men were beaten in both instances and, as a result, one of the teenagers had to be admitted to the hospital because of a wound incurred when he was hit in the forehead with a golf club. This gang preyed on gay men in the West Village because, as they phrased it, they wanted "to kill AIDS faggots." The assaults were reported to both the police and the Commission's Bias Response Team.

## THE COMMISSION'S RESPONSE

What can be done about all these problems? The Commission's response has been multi-faceted. First, we have made full use of local civil rights law and other protections which now exist and can be called upon to faciliate solving the discrimination problems faced by people with AIDS.

Second, we have come to recognize, as have most other organizations dealing with people who have AIDS, that many problems can best be solved by assuming the role of ombudsman. By the creative use of advocacy, many problems can be resolved or settled very rapidly. Obviously, when a complainant is very ill or in an emergency situation, even a relatively speedy, traditional investigation may be impossible or inappropriate. Advocacy thus remains the best route and must become more widely available to those who suffer this type of discrimination.

Third, we have recorded all the complaints which have been brought to us. By documenting these problems, our intention has been to obtain clear indications of the nature and extent of AIDS and HIV-related discrimination so that we can begin to suggest and provide specific remedies.

Fourth, education remains critical and surely the best offensive measure. Effective education can not only deter transmission of the virus, it can also prevent the fear and ignorance which lead to the discrimination which causes so much suffering and severely undermines our best public health efforts to control the epidemic. Our role in the education process has been to apprise people of the civil rights aspects of this crisis and to encourage or incorporate transmission information and health education, when appropriate, as part of settlements or training sessions. Additionally, this year the Commission launched an intensive education campaign, involving both print and video formats, designed to educate the public about the illegality of AIDS and HIV-related discrimination.

There is also a need to continue to tackle rough issues: What of the constitutional and medical ethics of mandatory or routine HIV antibody blood testing? And will coercive measures undermine our best public health efforts? What effect does expanded testing have on the incidence of HIV-related discrimination? Where should test results be recorded and who should have access to them? How can we ensure confidentiality and prevent further discrimination? Though there has been much discussion about this issue, it is still unclear what controls must be legislatively instituted. In addition, because we see a trend toward the establishment of AIDS-segregated facilities (which on the one hand may upgrade the level of care afforded an individual with AIDS, particularly where discrimination is still rampant) we need to consider whether this segregation is the best long-range solution or will it perpetuate the stigma and increase discrimination? We must also find a way to acknowledge that public health and human rights are inextricably intertwined and must be recognized as necessary allies in the battle to halt this tragic epidemic.

Although the CDC has recently expanded the definition of AIDS, public health officials and community spokespeople continue to cite a severe underreportage, especially among those people who have HIV-related infections which are not categorized as AIDS. ARC (AIDS Related Complex) is covered under the Human Rights Law's protections for the disabled, but this fact has received minimal and confused coverage in the news. We know that the number of people with ARC is many times greater than the number with AIDS. People with ARC are, in many cases, quite ill. However, because people with ARC don't officially have AIDS, they are not always eligible for the services and assistance available to people with AIDS. They too are encountering discrimination, and there is still a need for a body of knowledge regarding the experiences to which a person with ARC is subjected to be assembled.

It is the Commission's position that current legal protections must be fully utilized and that, where a lack of protection is noted, clear and comprehensive statements must be written into the law so that people with AIDS and those who are perceived to be high AIDS risks are fully protected from discrimination. The extent of bias and backlash and the devastating impact of the discrimination we have witnessed leads us to conclude that confidentiality must be rigidly adhered to; that mandatory testing is a counterproductive and dangerous measure; and that discrimination based upon the perception of AIDS-risk must also be considered illegal.

Advocacy, education and communication still remain our best tools. Willing, helpful and knowledgable advocates to act on behalf of those with AIDS, those with ARC and those perceived to be AIDS risks must be available in all areas. Governmental agencies, private institutes, community workers and care- and support-providers must communicate not only with one another but with the real experts -- those who have AIDS or ARC -- to understand their experiences and identify problems.

The impact of Acquired Immune Deficiency Syndrome on our society continues to evolve. But the need for effective and creative responses to the problems it poses is already apparent. It is hoped that the experience summarized in this report can be utilized toward this end. By examining, understanding and working with a solid base of information, the kind that can only be obtained through experience, the AIDS care and support network can extend in a logical manner. It is only by working together that we can hope to meet the pressing needs of all those affected by this crisis and to stem the tide of the stigma associated with AIDS.

CONTACTS WITHIN THE AIDS DISCRIMINATION UNIT:

| | |
|---|---|
| Keith O'Connor | 566-1826 |
| Katy Taylor | 566-5446 |
| Mitchell Karp | 566-7638 |
| Charles Brack | 566-0528 |
| Otto de Mendoza | 566-0817 |
| Azi Khalili | 566-0819 |
| Ernesto Castillo | 566-0395 |
| Richard Reynolds | 566-2017 |
| Amber Hollibaugh | 566-5178 |
| Alisa Lebow | 566-5179 |

** Statistics appear on the following page **

## STATISTICS ON AIDS-RELATED DISCRIMINATION COMPLAINTS RECEIVED BY THE NYC COMMISSION ON HUMAN RIGHTS DURING THE PERIOD JANUARY 1986 - JUNE 1987

| | YEAR | |
|---|---|---|
| Breakdown by group | 1986<br>Full Year | 1987<br>Half Year* |
| MEN | 228 (73%) | 232 (77%) |
| WOMEN | 64 (20%) | 62 (21%) |
| CHILDREN | 22 ( 7%) | 6 ( 2%) |
| **TOTALS | 314 | 300* |
| HIV status | | |
| AIDS | 152 (49%) | 158 (54%) |
| HIV POSITIVE | 22 ( 7%) | 45 (15%) |
| PERCEIVED AIDS | 137 (44%) | 89 (30%) |
| Type of discrimination | | |
| EMPLOYMENT | 80 (25%) | 88 (27%) |
| HOUSING | 40 (13%) | 42 (14%) |
| JUSTICE SYSTEM | 9 ( 3%) | 50 (17%) |
| INSURANCE | 5 ( 2%) | 11 ( 4%) |
| PUBLIC ACCOMMODATIONS | 141 (45%) | 99 (33%) |
| Public Accommodations Subcategories: | | |
| Hospitals and Health Care | 58 (41%) | 32 (32%) |
| Funeral Homes | 17 (12%) | 21 (21%) |
| Dental | 19 (14%) | 27 (27%) |
| Other | 47 (33%) | 18 (18%) |
| Incidents where HIV test was at issue | | |
| | 17 ( 5%) | 38 (13%) |

** 40% of all reported cases of AIDS and AIDS-related discrimination are systemic.

# Senate panel is told of Fla. family's AIDS plight

■ AIDS

[illegible]

Three of the four Ray children of Arcadia, Fla., are shown at a Senate committee hearing yesterday. Randy (left) and Robert, who are hemophiliacs, have tested positive for the AIDS virus. Their sister Candice does not have the virus.

[illegible]

# Senators told of family's plight with AIDS

[illegible]

AIDS, Page 16

WASHINGTON POST 9/11/87

# The Children & the Flames Of Fear

## In Florida, a Family at the AIDS Flash Point

By Myra MacPherson
Washington Post Staff Writer

ARCADIA, Fla.—An hour away from the burnt-out shell of their green frame house in this west central Florida town, Louise and Clifford Ray sat in a rented duplex the other day as their three sons raced to the pool, shouting, turning somersaults, laughing.

Theirs could have been any family on a summer weekend—except that this family lies at the center of the fear and passion surrounding the national debate over AIDS.

Late last month, a year after learning that their three sons—Ricky, 10, Robert, 9, and Randy, 8, all victims of hemophilia—were infected with the AIDS virus, after outlasting bomb threats and a long court fight to have them admitted to public school classrooms, the Rays awoke to find their house burning down around them.

The Rays, now in seclusion elsewhere, say they were firebombed by a community hysterical over fear of AIDS.

The citizens of Arcadia, a cattle town some 50 miles from Sarasota, fiercely deny the Rays were chased from the town, but acknowledge extreme civic concern over the deadly uncertainties surrounding the major epidemic of our time.

None of this was evident when the Ray boys, handsome blonds with deep tans, raced through the house, bursting with excitement at having made friends at the pool. Ricky sat restlessly on the couch and dutifully answered questions. School was not so easy the first of the week, but it was okay, he said. Randy felt bad when he got on the merry-go-round and other kids got off, said Ricky. What he missed was "being with other kids." What he wanted most was "that we can go back to school without somebody trying to burn down our house."

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Today the Rays will be in Washington to testify before the Senate Labor and Human Resources Committee in hopes of changing the climate and conditions regarding those who, like their sons, are infected with the AIDS virus.

When the Rays left Arcadia "with nothing but what was on our backs," they left behind a community united in its demands for mandatory AIDS testing of students and teachers in the public schools and for separate classrooms for the infected.

Everyone from the superintendent of schools to the town barber voices the same sentiments: No one

See ARCADIA, B8, Col. 1

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WASHINGTON POST

# AIDS and Arcadia

ARCADIA, From B1

ran the Rays out of town, the Ray children were offered a separate but equal education, and instead the parents exposed their children to publicity for personal gain.

No one from the community could have set that fire, they say. In fact, they say, a Ray family member may have set it himself.

Arcadian townsfolk are united also in their anger at the media for depicting them "as either crazy, lunatic, ignorant or redneck," according to Melody Patton, one of the advocates of AIDS testing in schools. "The only people who disagree with us," she added, "is the scum of the community."

Applause broke out at a Citizens Against AIDS in Schools rally following the fire when DeSoto County Commissioner John (Ed) Johnson demanded that President Reagan publicly apologize for making a "worldwide statement that brands us as a city without compassion." He was referring to Reagan's remarks in May that when it was learned that the Ray children had tested positive for the AIDS virus "the pastor asked the entire family not to come back to their church. . . . This is old-fashioned fear and it has no place in the 'home of the brave.'" The pastor says he did not ask the Rays to leave. Louise Ray says he did. "The only ones who know are my husband, me and the two ministers," she said, "and I'm not the one who will have to stand before God."

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Louise Ray settles into a couch to tell their story, her sentences punctuated by deep, uncontrollable yawns that make her blue eyes water. After weeks of tension, "my body's just caught up."

The Rays, 29, grew up in Arcadia and married as teen-agers. By the time Louise was 21, she had three children. Louise knew that her grandfather was a hemophiliac and that it was hereditary, passed on to males. "But I didn't know that much about birth control." Her youngest, a daughter, Candy, 4, is free of both hemophilia and the AIDS virus.

She remembers well that hot day a year ago when routine blood work revealed that Randy tested positive for the AIDS virus. "I was in a state of shock." Dr. Jerry Barbosa, attending pediatrician and hemophilia expert at St. Petersburg's All Children's Hospital, asked to test the rest of the family. "It never occurred to me what the results might be," Louise said. "Cliff and Candy and I were negative. But Randy and Robert were positive." Louise walked out of the hospital devastated.

"I kept thinking the first test was a fluke," remembered Louise. "But a second test also came back positive for the boys. . . . I didn't know there were stages, that you could have the antibodies, ARC (AIDS-related complex) and the full-blown disease. I just thought that was it; in two years my boys would all be dead."

Modern science has improved the outlook for the 20,000 hemophiliacs in the United States who have a hereditary tendency toward uncontrollable internal bleeding. A powdered antihemophilic clotting factor made from human plasma can now be mixed with sterile water and injected into patients to help them lead a nearly normal life. For years Louise Ray, a practical nurse now unemployed, injected the clotting factor into her sons. Louise knew that "with the medicine to control it there was no reason they couldn't live to be 110 years old."

The Ray boys, like more than half of America's hemophiliacs, were infected by the AIDS virus because the clotting factor they used was contaminated before blood screening for AIDS began in 1985. As many as a thousand donors can supply blood for a single dose of clotting factor, so the chances of hemophiliacs getting AIDS was far greater than the possibility of contracting the virus from a single blood transfusion.

"It's a shame," says Louise. "Without the medicine, the kids could die. With it, they could die."

While that shadow remains, the experts at the federal Centers for Disease Control (CDC) hold out some hope. They say that the risk of hemophiliacs actually contracting AIDS from the virus is far less than the other groups. Only about 3 percent have so far developed full-blown AIDS compared with far higher estimates for others. Also, despite the fear and furor, the chance of hemophiliacs spreading the disease through casual contact appears to be almost impossible. Says Dr. Barbosa: "There is not one single documented case in the whole country where AIDS has been transmitted through casual contact."

Yet, in some 10 cases in the country, AIDS-infected hemophiliac children have been admitted to classrooms only after protracted legal fights and court orders.

The Rays were no different. At their court hearing last month, a developmental/behavioral specialist testified that all the Ray boys are "suffering significant emotional distress in part as a result of their continued exclusion from the normal classroom setting . . . anxiety, feelings of rejection, anger, resentment and fear of social rejection."

Ricky, 10, once told his life story on a yellow legal pad, the first nine years condensed to four lines: "First I was born in Arcadia, Florida and when I was five years old me and Kirk had fun. And as the years when [went] by we meet new friends. But a few years later we found out we had the antibodies."

The rest is a poignant account of how he felt, particularly about not being able to go to school. "I was so mad at Mr. Browning [superintendent of DeSoto County schools] I was going to hit him and kill him so then there were no Mr. Browning. . . . I love Mr. Browning. . . . We are going to court."

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[illegible]

Danny Tew, president of Citizens Against AIDS in Our Schools.

Ray boys. But they say it's the parents' fault.

The town barber, Ron Waldron, 30, sits in the Arcadia Drug Store coffee shop sipping coffee. "They're cute kids and they all deserve a fair chance, not to be cared about. And a lot of people did care. We didn't run those people out. We offered them a teacher and an aide in their own classroom. What they'd offer that to my children instead of being in a class of 32. Who knows how many have the AIDS virus? With mandatory testing there'd probably be enough to start their own class."

Lawrence Browning, the superintendent of schools: "Those parents displayed what I consider questionable behavior—paraded their children in front of TV, had 'em in there taking pictures. If these were my children, they'd receive one heck of a lot more protection from the news media."

The Rays said the proffered "homebound" course, only three days a week for a total of nine hours, was insufficient. But Browning said: "It was highly concentrated . . . comparable to what only wealthy children got back before there were public schools."

One of the Rays' lawyers, Bill Earl, said emphatically: "If you think segregation is proper, it was a good offer. It was an offer to exclude—and there is a constitutional right to be in a classroom," he said, adding that the Rays' . . . had no disability guidelines for homebound students.

Says Louise Ray: "Even if it was the best education—and it wasn't—they would never be ready for the outside world. You need book education, but what you need more is interacting with others. You can't get that in isolation.

"If my children had something these kids were going to get, I would accept it in a heartbeat. But what they have they cannot give to them. I understand their fear. But what I cannot understand is people who will not educate themselves . . . will trust what the CDC says and the world . . . believes it."

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[illegible]

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empty storefronts. The action centers on the outskirts at the Clock Restaurant or a few blocks off the main street at the Arcadia Drug Store, where everyone greets everyone by name over morning coffee.

The Total Elegance beauty and tanning salon offers computer perming, braiding, porcelain nails, ear piercing, hair removal—and, in the back room, material on AIDS from the Citizens Against AIDS in Our Schools. The salon belongs to Danny Tew's wife Janet. Tew, a beauty supply salesman, is president of the organization; Melody Patton the vice president. Patton was recently on ABC's "Nightline," and the press, she says, "has it all wrong. The issue is AIDS in our schools, not the Rays. ... There's probably a lot more who has AIDS. We're looking for the ones who aren't identified." Tew and Patton and their 700 members are convinced that—contrary to experts' opinion—the AIDS virus can be spread through casual contact. Stacks of an American Red Cross pamphlet sit on the counter outside Browning's office, noting, "Not one case of AIDS is known to have been transmitted in a school, day-care or foster setting. AIDS is not spread through the kind of contact children have with each other, such as touching, hugging or sharing meals and bathrooms."

Patton and Tew remain unconvinced. "Not yet," they say.

"Kids swap food, lollipops, pee all over toilet seats. I've never seen a child able to vomit or bleed from a cut and not get it all over the place," says Patton. She tries to tell her elementary school daughter not to hug her schoolmates. "I cannot get through her head the potentially dangerous situation." Tew nods. "Who says you can't get it from hugging? ... No one knows." When doctors point out that families as close as the Rays have not contracted the virus, Tew replies that AIDS is too new. "This disease can lie dormant," he says. "There's just too much left unknown."

Doctors testify the risk is small, but Patton says, "When you're talking about my children I don't care how small the risk is."

Dr. Barbosa, an untiring fighter for the rights of all hemophiliac children, can hardly control his anger when he listens to the parents of Arcadia. "My children play, swim with the Ray boys," he says. "Do you think it would ever cross my mind to expose my family to something like that? In order for you to get AIDS you have to *try* to get it—through sex or needles."

But the bible of many in Arcadia is a book called "The AIDS Cover Up?," which puts forth, among other things, that the CDC, the American Medical Association and the Gay Task Force have underreported on AIDS to hold down panic in the country.

The author, Gene Antonio, is so fearful of contracting AIDS that, he stated in a radio interview, when he is served by an effeminate male flight attendant, he makes certain the attendant handles only wrapped food.

Superintendent Browning says the book is a "devastating" revelation. Rick Wastron, the barber, believes the risk of casual transmission is actually great. "They lied to us about Watergate, the Iran-contra affair, Vietnam for 15 years. ... All dentists now wear gloves, and in hospitals they wear masks and gloves when treating AIDS patients. Are they afraid of something? They're doctors."

* * *

In the wake of international publicity, the town of Arcadia is defensive, holds meetings on how to handle its image and tells everyone, as Sheriff Joe Varnadore says, that its citizens "are the salt of the earth."

Bitterness at the Rays has united the community; politeness drops and words turn ugly—they have been referred to as "poor white trash" and Patton says "everybody knows they are low-hygiene-type people."

"They had nothing before," says Wastron. "And now they got a new truck and new car." Sheriff Varnadore says the fire is being treated as arson, based on evidence, and that a report will be issued shortly.

Tew says, "Ask yourself, who stood to lose the most by that fire? It hurt this committee's cause much more than it hurt the Rays. The implication by Ray that we started the fire got them sympathy from millions of people plus money—and we didn't do it. We want to get our cause nationwide and we could only do that with the press."

The Rays have set up a Remember the Children Inc. fund to provide support for others in similar situations and have requested that any donations from the people of Arcadia go to AIDS research. "They don't have a new car, don't have a new truck, don't have a house, don't have anywhere near millions. It's coming in from all over the country in $5 and $10, at most about $50,000," said lawyer Earl, who with his wife Judy Kavanaugh has become friends with the Ray family. "The bulk of whatever they keep will go into a trust fund for the boys.

"The people in Arcadia are grasping at straws."

* * *

On the outskirts of Arcadia, the burnt-out hulk of the one-story green frame house, with the "crime scene" sign, stands as a reminder. A child's wagon sits outside in the debris in a neighborhood of trailer houses. Cliff Ray says the fire "started inside the house, but the thing is our house never had no lock on it. The jalousie windows just flip open. That house is the last thing my father had. He give it to us kids. That's the house my wife and I got married in ... a lot of memories went up in smoke."

Nearby neighbors, Louise said, "never associated with us" after they learned the children were infected with the AIDS virus, "but they were nice. From a distance. They would wave at us—which made us feel good. They had a little compassion for what we were going through."

She said she disclosed the results of the AIDS tests to her pastor and the school last fall. All four children were removed from the classroom but Candy was soon allowed to return. Homebound instruction began for the boys, although Barbosa and the pediatric consultant for children's medical services of Florida advised that the boys should be returned to the classroom. They were taught at home last winter. The Rays worked on separate shifts until Clifford Ray—who has been a truck driver [illegible] because [illegible] moved.

In February, they moved briefly to Bay Minette, Ala. "Looking back, I realize we were just running," says Louise. "The boys went to school about two weeks and then we started getting calls from the school asking why they were so behind. I asked if they had gotten the records from Arcadia yet and they said no. Well, when they came, they had the recommendation for homebound and why. They said that Candy could stay but the boys couldn't."

Had the boys been able to stay in the classroom, Louise says, "we probably would have stayed there. I had a good job in the hospital. Cliff was working on maintenance at our apartment building."

Instead, the family returned to Arcadia.

Barbosa encouraged them to tell their story at a hearing for another hemophiliac child who had been removed from another Florida school system. From then on, lawyers guided the Rays as they requested enrollment in regular classrooms and were refused. Until the hearing, the boys were taught at summer school in a separate classroom.

The Rays come down on the side of voluntary testing for AIDS and feel "a doctor should know" who the infected children are "and watch for symptoms." But the penalty of disclosure is so severe, says Cliff, "what happened in Arcadia will just cause people with problems like ours to go underground even more."

"The boys know they probably could die. We haven't kept it from them," Louise adds. "They are taught not to let anyone touch their blood under any circumstances, even though it's a minute chance that anything could happen if someone else has a cut," Cliff says. "We don't want to jeopardize nobody else."

He looks at his sons as they dash in for an inner tube for the water, then slam out the door. "I've been telling them all along they can't have a healthy sex life," says Louise. "That's a terrible thing to tell a 10-year-old he can't have kids. But Ricky says he'll adopt."

The judge, in "strongly recommending" that the boys be returned to the classroom, issued a statement with which no one could quarrel: "The Ray boys have already been dealt a hand not to be envied by anyone ... at their young ages [they] are having to face two potentially life-threatening diseases. This is more than most people face in their entire adult lives."

This week, Sarasota County schools voluntarily adopted a policy for AIDS-infected students that is almost a mirror image of the judge's ruling and have said they would be happy to take the Rays, who are expected to stay in the Sarasota area. They will announce their plans Monday.

As for the long-term implications of their lives together, Louise Ray says, "If I really sat down and thought about the fact that my kids could have AIDS, I don't know if I could handle that right now.

"But I have to keep thinking at least I had them this long. Kids are really gifts.

"If he takes them, he's got them right."

Senator **Metzenbaum**. The hearing stands adjourned.

[Whereupon, at 11:52 a.m., the committee adjourned subject to the call of the Chair.]

# AIDS FEDERAL POLICY ACT OF 1987

WEDNESDAY, NOVEMBER 18, 1987

U.S. Senate,
Committee on Labor and Human Resources,
*Washington, DC.*

The Committee met, pursuant to notice, at 10:38 a.m., in room SD-430, Dirksen Senate Office Building, Senator Edward M. Kennedy (chairman) presiding.

Present: Senators Kennedy, Harkin, Weicker, and Pell.

## OPENING STATEMENT OF SENATOR KENNEDY

The Chairman. The Committee will come to order.

Six months ago, a bipartisan coalition joined together to introduce S. 1220, the first comprehensive legislation in the Federal Government's war against AIDS. This measure was designed to launch an effective attack against the spread of the AIDS virus through accelerated research efforts and widespread education campaigns and to develop alternative treatment networks to care for people with AIDS.

On July 29th, after hearings and extensive debate, and with a shared commitment to take action on the most critical public health issue of our day, this Committee reported the legislation unanimously, and it is now ready for action by the full Senate.

Since the Committee acted, 3,000 more Americans have lost their lives to this devastating virus, and 8,000 more have been diagnosed with AIDS. In urban centers and small towns across this country, the disease has continued to spread, infecting individuals in every walk of life and threatening us all with a national health catastrophe.

The AIDS epidemic has already touched the lives of millions of our American citizens. It is even now casting its shadow over the generations to come. Yet as the toll continues to mount, the Federal Government continues to fall short of its obligation to demonstrate effective leadership in the face of this national emergency.

Last May, a broad spectrum of medical, public health and community-based organizations testified before this Committee that until a cure is found, preventive education is the most effective front-line defense against the spread of AIDS.

To support this strategy, Congress appropriated $20 million in July for a nationwide, door-to-door mailing of AIDS prevention information. Yet despite public and professional support for this approach and a specific Congressional appropriation, no such mailing has occurred, nor is one planned in the future. And that is only one example of the present disarray in our efforts to achieve a coordinated Federal aid program.

AIDS is a challenge of unprecedented proportions and necessitates a comprehensive authorization program adequate to meet the need.

The four-point plan we have proposed will do the following: first, put the full genius of our scientific community behind the search for a vaccine and a cure; second, provide all Americans with accurate information about the risk of AIDS and the means to protect themselves; third, develop effective treatment networks for people with AIDS that are more economical and appropriate; and fourth, assure that all Americans have access to voluntary and confidential AIDS testing and counseling and are protected against discrimination.

The only way to fight AIDS effectively is with sound public health policy, not with ideology. Irrational exercises in fear and prejudice will serve only to drive the epidemic underground and encourage its wildfire spread.

In the final analysis, history will be a remorseless judge. If we fail to use common sense and compassion in meeting this challenge, if we seek to condemn and punish others, we may well be condemning ourselves to unparalleled repercussions. We cannot afford coercive approaches that defy sensible public health policy and that only divert our attention and resources.

In today's hearings, we will focus again upon the glaring human cost of current inaction. Every day, that cost is measured in untold suffering and lost lives, and every day we are living on borrowed time.

I hope the testimony that we hear today will help to convince the Congress and the country that the time for responsible action is long overdue. Experts and practitioners in medicine and public health are virtually unanimous in their prescription for comprehensive action. The only ingredient missing is the courage required by Congress to act before it is too late.

We know what needs to be done, and now is the time to do it.

[The following was submitted for the record:]

*from the office of*

# *Senator Edward M. Kennedy*

*of Massachusetts*

REMARKS OF SENATOR EDWARD M. KENNEDY
TO THE NATIONAL INSTITUTES OF HEALTH
DIRECTOR'S ADVISORY COMMITTEE
"A PERSPECTIVE ON AMERICA'S BATTLE AGAINST AIDS"

For Immediate Release
November 19, 1987
CONTACTS: Paul Donovan
Robin Backer
(202) 224-4781

I welcome this opportunity to speak to you this morning and to give you a perspective from the Senate on the nation's most pressing health problem, acquired immunodeficiency syndrome. AIDS, if nothing else, has been a plague for our times.

[illegible]

[illegible]

I want to take a moment to [illegible] to this [illegible] worked with them. And, it is thanks to the collective efforts of the biomedical research community, that we have any grasp at all on the problem of AIDS. Only with your brilliant success in identifying the virus could we even begin to estimate the full magnitude of our problem.

And it is our problem. Unfortunately there are too many Americans -- including some in high places -- who don't yet believe that AIDS is a challenge for us all. They speak in terms of "building fences" around AIDS and those who carry the virus. They seem more interested in compiling lists and collecting names and attempting to legislate personal behavior, than in pressing forward with research and education programs that might actually change behavior.

I do not have to tell you that unwarranted fears about AIDS already account for a long list of senseless, individual tragedies: not just the loss of employment or housing by many people with AIDS, but their utter abandonment -- even by their closest friends and family. This at the time when a human being is most in need of help: when battling sickness and facing death.

The price we pay for unwarranted fear of AIDS is not just measured in senseless suffering and discrimination. It also threatens to distort the long overdue effort to devise a sound public policy in the critical areas of education and prevention.

Fortunately, these prejudices have not spilled over as severely in the area of biomedical research, which has been one of our principal successes. There is every indication that investigators are now starting to win some of the battles against this virus in the test-tube -- and perhaps even in the clinic. But all of us will be the losers in the overall battle against AIDS, unless we take a strong and immediate stand against the growing and pernicious epidemic of prejudice.

We must redouble our efforts to translate the hard-won scientific understanding of AIDS into language that every American can readily comprehend. As leaders of the biomedical research community, I urge you all to pursue every possible strategy for communicating -- as convincingly as possible -- the essential information about how the AIDS virus is and is not spread. We need to find new and better ways to explain to the public what medical science knows about the AIDS virus. As leaders in medicine at this nation's finest universities and medical schools, you can lend your voice to the effort to establish sound policy in your own communities.

With the possible exception of the effort to conquer space, there has never been such a public hunger for knowledge and understanding of extremely sophisticated science. Though AIDS is a terrible human tragedy, it brings with it an unprecedented opportunity for millions of Americans to understand the vital role and the great potential of basic medical research.

It is true that some are scheming to use the AIDS health crisis as an excuse for advancing political agendas that have everything to do with ideology and nothing to do with public health. But the overwhelming majority of Americans reject that false approach. They share two goals -- the development of a vaccine to prevent AIDS, and support for effective means to halt the suffering and death.

The entire world looks to this country to take the lead in ending the AIDS nightmare -- as fast as humanly possible. They do so because of our nation's outstanding support of fundamental research and our commitment to medical excellence. No other nation even comes close to making the investment in science that is made -- year in and year out -- by the American people.

As we confront this new and lethal threat to the public health, it is no surprise that citizens increasingly turn here, to the medical research establishment they assisted in assembling, for urgently needed help and hope. Congress is fully prepared to fund whatever is needed to develop medical solutions to the problem of AIDS. And that priority is widely shared by the vast majority of the American people.

The people's faith that research will find a solution to end this crisis is a direct reflection of what has made this country great. The same "can do" attitude that landed a man on the moon and that conquered polio and eradicated smallpox is at work again. The American people are convinced that research community can get the job done on AIDS. They want action and they are ready to pay for it.

It is the intention of the appropriations committees in both the Senate and the House to provide about $950 million for the overall AIDS effort in fiscal year 1988. This represents an increase of $180 million above the administration's budget request. Half of the total amount is earmarked for the National Institutes of Health, and President Reagan himself has indicated that AIDS funding warrants top priority.

Before the end of the current session of Congress, I hope to bring to the floor of the Senate the bipartisan "AIDS Research, Information and Care Act", which I introduced earlier this year. The legislation is sponsored by Senator Orrin Hatch, Senator Alan Cranston, Senator Lowell Weicker and many others. It has received the unanimous approval of the Senate Committee on Labor and Human Resources, and companion legislation is being prepared for introduction in the House by Representative Henry Waxman.

The bill requires the Secretary of Health and Human Services to declare AIDS a public health emergency, and to double the size of the health emergency fund available to the Secretary.

It also requires the administration to submit a comprehensive annual plan to Congress for combating AIDS, with special attention to education and risk-reduction programs. We also ask the Secretary to examine the possible need for special consortia to facilitate cooperation in AIDS research between government, industry and universities.

To assist the Director of NIH in the task of planning and coordinating the overall AIDS research effort, the bill calls for the creation of a special Director's advisory panel on AIDS. I am aware that Secretary Bowen recently decided to establish a similar panel. I look forward to carefully reviewing the names of those nominated by HHS to serve on this critically important committee.

Congress feels strongly about the "experts" we recruit for this type of duty. AIDS represents an extremely complex scientific -- and public health -- problem. In searching for the shortest path to successful results, we need the expertise of those who are already "up to speed" on the issues. I'm sure you are aware of the concerns in this area about the Presidential Commission on the HIV Epidemic. The last thing we need is any attempt to politicize the scientific and medical issues of the problem of AIDS.

The bill coming before the Senate will also provide specific authorization for many of the impressive AIDS initiatives already in progress at the NIH. I commend the cooperative efforts of Dr. Wyngaarden and the NIH AIDS Executive Committee in mobilizing the resources and energy of 11 different institutes to meet the AIDS challenge. To further advance that effort, our legislation also calls for the formal creation of a Core National Research Program on AIDS within the National Institute of Allergy and Infectious Diseases.

As with the designation of lead institutes for Aging and Arthritis, we believe it is essential to assure long-term support for the AIDS programs now supported through NIAID. The AIDS Treatment Evaluation Units, Clinical Study Groups, and the Cooperative Drug and Vaccine Discovery Groups are all critical in the battle to end this disease. It is also our intention in Congress to assure that the administration provides a swift response to requests for the personnel and facilities needed to operate these core programs.

NIH-wide, the legislation also authorizes an increase of up to 350 full-time employees. Appropriations are not enough -- you must also be able to hire qualified professionals to manage the programs, or the work will not get done.

As members of the Director's Advisory Committee, you are the trustees of our government-supported biomedical research effort. I look forward to working closely with you in the months ahead to advance the priorities we share. I speak for literally millions of concerned and compassionate Americans in urging you to do all within your power to find us the answers we need for AIDS.

The CHAIRMAN. Senator Harkin.

### OPENING STATEMENT OF SENATOR TOM HARKIN

Senator HARKIN. Thank you Mr. Chairman. I would like to take just a moment to commend my distinguished colleague from Massachusetts for calling this hearing today. No congressman or senator has done more to heighten public awareness of AIDS. He has approached the issue with reason and compassion, and with his persistence I'm confident that the Senate can work quickly toward addressing some of the most urgent, as well as the long-term needs of this nation that are associated with AIDS, through passage of S. 1220.

I'm particularly grateful for this unusual opportunity to discuss potential floor amendments in a hearing where we have the advantage of expert counsel. I look forward to the testimony of our witnesses this morning, please continue.

The CHAIRMAN. Our first witnesses this morning are certainly not lacking in courage, and I welcome them to our hearing. We will first hear from Michael Sisco, who is now living in Martinsburg, West Virginia. Michael has AIDS, and he has recently decided to go public and to tell his story.

After we hear Michael's statement, we will hear from Mary Jane Edwards, from the Los Angeles area, who lost her own 35 year-old son to AIDS about three years ago. Ms. Edwards has formed a national organization of women who are mothers of AIDS patients, and she will describe not only what she went through with the loss of her own son, but will give us her perceptions of this problem as seen through the eyes of so many suffering parents.

I appreciate very much your both taking the time to join us here today, and Michael, why don't you begin?

### STATEMENT OF MICHAEL SISCO, MARTINSBURG, WV; AND MARY JANE EDWARDS, FOUNDER, MOTHERS OF AIDS PATIENTS, LOS ANGELES, CA

Mr. SISCO. Mr. Chairman and Members of the Committee, first, I would like to thank you for the opportunity to speak before you today.

AIDS is a subject that must be dealt with. There are hundreds of thousands of people who could die. AIDS is a disease that kills and destroys. But with the right attitude and funding, it does not have to. We can beat this disease.

We must start by educating the public about the do's and don't's of AIDS and how you can get it and what to do once you get it.

I have been through hell to get here. I have been driven out of my home town and away from my family, a family who does not understand exactly what is going on.

We people who have AIDS have a hard time with this disease, plus we must deal with a society that does not understand. It is very hard to live with a terminal illness much less to lose all those we love, like I have. I know that my family loves me, but they must hide this love to live in their home town. This must be stopped.

I went through what my therapist said was a "social death." So in a way, society murdered me. Did they stand trial? No. They continue to harass my family and drive us further away from each other.

We must educate these people and all people across the country and the world. The world looks to America as an example, and we must stand up and educate these people so they understand AIDS.

Educating people is a very important way to defeat this disease. We must overwhelm people with information about this disease. This education must be in the simplest form so that everyone will be able to understand.

I would like to close by saying that there is hope and that everyone should not, under any circumstances, give up hope.

I have found hope and love with someone who is very important and special in my life, and in the end, I will be the victor over this disease, but only with the help of my friends and family and lover.

Please remember we were all created equal and that God loves everyone.

Thank you.

The CHAIRMAN. Thank you, Michael.

Let me ask you a few questions before we go on to Mary Jane Edwards, if I could, please.

I am always mindful of the fact that it is difficult for individuals to talk about their health needs. It is also difficult for parents to describe some of the needs of their children. I think this is so because people generally consider health challenges to be private matters. But we want you to know that by your willingness to talk with us today, we are very hopeful that we can advance what you have outlined in your testimony, and foster a better understanding and greater awareness of what you are going through and others similarly situated.

I believe that the American people are an understanding and compassionate people, and perhaps we can reawaken or rekindle these emotions in order to be more responsive to the human tragedy which is affecting so many people in our society.

I thought we might just review some of the harassment you have been experiencing. You have been through some very hard times, as you say, not only physically but emotionally and I think it would be helpful if you would be willing to recount, in some detail, some of the experiences you went through in your home town. Maybe you could take a few minutes just to recount some of the ways you were treated in the home town after word got around that you had AIDS. Maybe you could tell us a little bit about what happened with your aunt. I think we might be interested in that.

Mr. SISCO. First, the community started a petition to keep me from living in this certain, little, small community. My relatives had been told in January that I had the disease, and they thought that when I came back——

The CHAIRMAN. Who told them?

Mr. SISCO. I called them and told my father and two of my sisters, and they told the other members of the family. They were supportive over the phone, but once I came back to West Virginia, they had decided with the help of the community that they did not want me there. So relatives posted no trespassing signs and basically asked me to go back——

The CHAIRMAN. Who put the no trespassing sign on your aunt's lawn?

Mr. SISCO. My mother's own sisters.

The CHAIRMAN. And who was that directed at?

Mr. SISCO. That was directed at me, directly.

The CHAIRMAN. I mean, people put no trespassing signs on houses generally to keep trespassers out, but in this case it was directed to you.

Mr. SISCO. Yes.

The CHAIRMAN. And then there was a time when some members of the community thought you worked at McDonald's.

Mr. SISCO. Yes, McDonald's. I have never been inside the building.

The CHAIRMAN. But you were made aware that some of the members of the community thought you worked there?

Mr. SISCO. Yes. They ran a statement in the paper that I did not work there, and they invited the public to come up and walk back into their kitchen and watch them work.

The CHAIRMAN. And what happened at the McDonald's facility when they thought you worked there?

Mr. SISCO. They boycotted the McDonald's. That is when they had the open house where everyone could walk back in and watch the people work in the kitchen.

The CHAIRMAN. And I understand you were arrested once; is that correct?

Mr. SISCO. Yes, I was.

The CHAIRMAN. And they were going to put you in jail overnight?

Mr. SISCO. Yes. They were going to put me in jail, and they decided they would just put me in some kind of little room so I could sit there until my father would come and get me. I sat there alone, and they came in with gloves and masks and gowns on.

The CHAIRMAN. So they would not even put you in jail, they made you go into some different kind of cell.

Mr. SISCO. Some kind of little holding cell or something.

The CHAIRMAN. And then there was an incident regarding the grocery store; is that correct?

Mr. SISCO. Yes. They had called my father and told him I was in jail again because I had been licking the produce, the vegetables. And I had been sick for the past couple of days and was not even there.

The CHAIRMAN. Who spread that story?

Mr. SISCO. I have no idea. I have been told it is my own relatives.

The CHAIRMAN. So someone, perhaps your own relatives, was telling the town people that you were contaminating the fruit, is that right?

Mr. SISCO. Yes.

The CHAIRMAN. And what happened? Did people get concerned about that?

Mr. SISCO. Yes. The local law enforcement came up and talked to my sister and told her that they should restrain me from going out into the public because the community was not going to stand for it, and that they would have to do something with me if I continued to go out in public.

The CHAIRMAN. So did you gain a sense of general isolation from the activities that were taking place, through the no trespassing sign on the lawn of your aunts' residence, the avoidance of the McDonald's and the rumors that were being spread about the activities in the grocery store? Did you have a sense of general isolation?

Mr. SISCO. Yes. After the incident with the local law enforcement, I stayed in for about six weeks, did not go anywhere, and kind of just wished I would go ahead and die. But I seemed to get healthier every day.

The CHAIRMAN. Did you have to consider moving out of town?

Mr. SISCO. I had nowhere to go, until my therapist told me of a hotline in Charleston, West Virginia. I had no idea that there was any help in West Virginia at all. I did not think I would need it. I came home to be with my family. I was not really concerned or worried about looking for any kind of AIDS help. I thought my family would help me.

The CHAIRMAN. Did your family help you find a new place to live?

Mr. SISCO. The State Health Department did find me a host home, and I stayed there for three months.

The CHAIRMAN. You were recently the subject of a magazine article, and you were on television a few days ago, and you have been good enough to join us here today. In the magazine article, you were identified under a false name to protect your identity, and now you have obviously decided to go public.

Tell us what finally prompted you to go on national television and appear here at our hearing?

Mr. SISCO. I think it is very important that the people who deal with this first-hand stand up and educate the rest of the country as to what is going on. It took a long time for me to accept that I had the disease, and then once I did, I was afraid, and I wanted to hide, and then I decided I have nothing to be afraid of; I need to stand up and educate as best I can.

The CHAIRMAN. Have you gone through any additional hardships as a result of going public with your story?

Mr. SISCO. Yes. When we came back to Martinsburg Monday night, there was a little delegation of people there, friends and family of my lover, and they asked us to move; they asked us to leave Monday night, to leave Martinsburg. And we will be moving again. I am not sure where, but I will be moving again somewhere that I feel is safe.

The CHAIRMAN. So you are not even living in your home town?

Mr. SISCO. No. If you watched the Oprah Winfrey Show, they don't want me there.

The CHAIRMAN. Would you prefer living in your home town?

Mr. SISCO. After everything that has happened, no, I don't want to go back there. I see that my family cannot handle it. Like I said earlier, they love me, but through the society they have to hide that love, and I do not want to put them through that.

The CHAIRMAN. Do I understand that you actually went into hiding at one point?

Mr. Sisco. Yes. There were threats on my life over the local radio station, and when the health department found me a host home, I went into hiding, and even my family did not know where I was at until two months later.

The Chairman. You have talked about education. What do you want people to know?

Mr. Sisco. I would like them to know that if they are not a hemophiliac and they are not a homosexual, and they have safe sex and they practice safe sex, that they are not going to get this disease, and that they do not have to be afraid of people who have it; that you have to have sex with these people, or have a blood-to-blood contact to get this from the people who have it. There is no reason to quarantine us or ship us off onto some island. It is a very hard disease to get. I mean, you basically have to work at getting it. You do not just reach out and touch someone and get this disease.

And it can be put in plain and simple words so that people as low as in the fifth grade can understand. They have to be taught early.

The Chairman. Is there some kind of education, in terms of family relations, that could help families deal with a personal AIDS experience. Is there some understanding that people ought to have to help them deal with a sense of compassion and love for a family member with AIDS?

Mr. Sisco. I recently read a book titled, "When Someone You Know Has AIDS." For anyone who has been around anyone who has AIDS or is going to be around them, that is a handbook that can be and is very helpful. It tells you how to love this person, how to make them feel as normal as possible, because the more normal the environment, the longer the person is going to live.

My oldest sister has read it, and I lived with her, and she was not afraid of me. The only problem we had is she has a little daughter who is about two years old now, and she went through the biting stage, where she was biting people, and we had to watch out then, but other than that, I lived and existed in that family normally until the society ran me away.

I cooked for these people, I cleaned for them. I even went out and helped my brother-in-law make some money for us, cutting grass and things, when I felt like it.

The Chairman. You think there is a lot more to know, both about the nature of the disease and also about how to treat people who have it.

Mr. Sisco. I think there is a lot more to learn about how to treat the disease itself. I think we basically know how you can get it. And if people would just read, just educate themselves. You cannot pound it in their heads. You can give them the information, and they themselves have to read.

The Chairman. Do you think that the public has gotten a lot of misinformation or wrong information about how AIDS can be transmitted?

Mr. Sisco. I think it is not misinformation; I think they just let their imaginations get carried away. I think they listen to some religious fanatics who are homophobic, and they let that make their decisions for them.

This is not a homosexual disease. This disease does not have any bias towards anyone. And I think the major thing is the fear of homosexuals. It is not the fear of AIDS; it is the fear of homosexuals.

The CHAIRMAN. Ms. Edwards, would you proceed, please?

Ms. EDWARDS. Thank you very much for inviting me to Washington to testify.

Mothers of AIDS patients are not concerned about statistics. They change daily. But the projection for 1991 is not comprehensive; it is just terrifying.

We are concerned about the lack of assistance we have in extending our children's lives. We want them to have a future. It is difficult to speak of a future when five mothers in our group lost their sons this past week, and two more young men were diagnosed HIV-positive.

Discrimination against our next generation of Americans is one of our major problems. Who cares, particularly a mother, how her child became ill? We stand strong beside their beds to give comfort and love, and wish a bowl of chicken soup and a kiss on the forehead would make it all better. But AIDS does not work like that.

There is no prospect for a cure at the moment, and the projection is very bleak. AIDS destroys immune systems and ends lives before the natural order of our universe is carried out.

The threat of quarantining our children is ludicrous, financially impossible, discriminatory, and no mother in America will stand idly by and allow anyone in our Government to implement such an atrocity.

Education is our greatest advantage. I will never have AIDS even though I cared for my son when he died of AIDS in 1984. I am educated, and I am aware of how it is contracted. I sometimes feel half our population live in caves, never reading or listening to all the information available to arm ourselves against this plague. Wake up, Americans. This is a public health problem, not a gay disease. There is nothing gay about AIDS. It is grim and it is devastating.

Hospitals are for acute illnesses, not prolonged debilitating disease. Let us establish hospice units nationwide and get AIDS patients out of $1,200 a day rooms and into a medical, home atmosphere.

We desperately need in-home nursing so the family and friends can be involved in the patient's care. AIDS patients need their loved ones near them as their life ebbs daily and their bodies are diminished to skeletal-like stick figures.

It is of necessity that the Government adjust our budget to include this nursing care for HIV-positive and ARC patients. We must have supplemental funding immediately. Try as we may, mothers cannot become registered nurses overnight. We are the basic caregivers.

The release of experimental drugs should be of utmost importance as most patients are willing to try anything to extend their lives. I realize the pharmaceutical companies are working around the clock for a cure, but we mothers are very impatient for help.

Federally-subsidized catastrophic health insurance for AIDS and ARC patients should be mandatory. It is appalling how many young men are living in the back seats of their cars without medication because their insurance was cancelled when their employers fired them on learning they had AIDS or were just tested HIV-positive.

Why should the major amount of benefits from an insurance company be used up by an ARC patient before he has full-blown AIDS? This happens daily. Diagnosed HIV-positive and ARC patients are not recognized by Atlanta's CDC as being very ill, therefore are not considered for Social Security, which takes months to receive, and most P.W.A.'s—persons with AIDS—do not have months. I have seen too many die before full-blown AIDS is even diagnosed to believe that.

P.W.A.'s want to continue their jobs and their responsibilities, but need financial help with staggering medical bills. Do you wonder why so many P.W.A.'s are underground about AIDS?

ARC is as deadly as AIDS, and until the CDC recognizes that as a fact, the insurance companies will falter along the way.

We must open our arms, our hearts, and our purse strings to conquer this lethal disease. Please consider D. Stephen J. Kraus' of Atlanta CDC report that, "One in every 80 men in America are HIV-positive." This could be your son, or it could be you. But that does not eliminate the threat to your daughter, your baby or your wife. No one should have to die with the stigma of a socially unacceptable word such as AIDS on their death certificate.

Let's hold hands across America and conquer AIDS through education, Government funding, and unconditional love. If you remember nothing else that I have said today, remember this, and I quote: "When we lose our parents, we lose our past; but when we lose our children, we lose our future."

Thank you.

The CHAIRMAN. Thank you very much.

Ms. Edwards, could you tell us how you decided to form this organization and tell us a little bit about how it works?

Ms. EDWARDS. My son became ill in 1982, and that was when the first scare of AIDS was out there. I did not have anyone to talk to except my son's friends, two girlfriends, and my husband. That was my support system. And I kept thinking I was the only mother in the world who was going through this, who was losing her child, and I was the only one with a broken heart.

And it so happened a lady who lived just a few miles from me went through the same experience. I went through it in September of 1984; she did in November of 1984. We left our names at the AIDS hotlines, the AIDS Project Los Angeles, and we said we need to talk to a mother, we need to work through this.

She called me, and we discussed it for about three months and decided we were committed to never allowing another family to go through this alone, without support, without someone to hold hands, to cry with, just to talk to.

So in March, it will be two years. We started with two women. We now have over 300 families in Los Angeles and about 200 P.W.A.'s that we talk with at least once a week. We have support meetings. We have support bereavement meetings for the ones that have already lost their children. We go to any length to support a family. This is not just mothers. This is families. Siblings are wonderful support for these young men. They really rally around them.

Fathers are terrific, too, once they have gotten over the problem of dealing with the homosexuality; they are always there for them when they are ill.

The **Chairman**. To your knowledge, is this the only program that you have in L.A., or is there a national program?

Ms. **Edwards**. There are support groups all over the United States. There is not a program just like ours, not a Mothers of AIDS Patients.

The **Chairman**. You are trying to turn that into a national program, is that right?

Ms. **Edwards**. Yes. We have groups started in several States. In Massachusetts, we have three mothers that we contact and work with, and they have been very beneficial.

The **Chairman**. Very good.

What sort of things do you try to do with mothers of people with AIDS? I mean, if a mother gets hold of you in L.A., what kind of support are you able to give them? I suppose it depends on what their special needs are.

Ms. **Edwards**. They want to tell their story. They want to tell the story of their son, how their heart is breaking. When they call us, it is at least an hour conversation, listening to this woman cry and say, "I am broken-hearted."

Then we have another case of a woman who called, and her son had died. She did not have $150 to have his body cremated so he could be buried. We rounded up $150. We are not funded. We have incorporated, and we are hoping to get some funds.

We had a woman whose son was in Juneau, Alaska, and she wanted to see him before he died. We managed to get together $500 to send her to Juneau to be with her son two weeks before he died.

These are the things that we will be doing. But mostly it is a support group. We have been there, and we know what listening means. We know what hand-holding means.

The **Chairman**. How about a situation where the parents do not want to see their children? Do you have any of these kinds of situations?

Ms. **Edwards**. We have about one-third of our young men in hospitals. We work out of three different hospitals in Los Angeles. About one-third of our young men, the parents have written them off and said, "We cannot deal with your death."

Well, we try to contact the parents and say, "Your son is not dealing with his death very well, either." But if they are not there, the MAP mothers are always there for them. We go to the hospitals; we hold their hands; we are there when they die, and we help the lover or the friends who are going to take care of the remains.

We give them birthday parties. We take them home with us. We are having a Christmas party for 120 P.W.A.'s who may not be here next Christmas. We are making 120 red Christmas stockings for them, because we want to do something for them. We want to be the surrogate mothers where their mothers have let them down.

The **Chairman**. You have heard Michael's story. Is his situation unusual, or is it fairly common?

Ms. **Edwards**. In smaller towns in America, it is common. So many of the mothers come from out-of-town to Los Angeles to be with their son, living in the California area. They don't want to go back home and tell their relatives and friends that their son died of AIDS. They really would like to have the death certificate altered and not read "AIDS", and they don't plan to go back and tell anyone. So many of them just say he died of leukemia or cancer—because their businesses would be in jeopardy.

The **Chairman**. Their businesses would be in jeopardy, because——

Ms. **Edwards**. People would boycott their places of business. If they knew the son died of AIDS, they would think the parents had it, too. This is the mentality of the smaller towns. I hate to say that. But until they have something in their hands that they can read and tell them, they are not going to listen to radio and television, and they are not going to read the paper. They need something in their hands that is sent to their home that they can read, that tells them that they should have no fear of this disease. It is very difficult to get AIDS.

The **Chairman**. What is the message you think mothers of AIDS patients would most like to convey through you at this hearing today?

Ms. **Edwards**. I wish all parents could love their children unconditionally. Forget about how they got it, when they got it, what they did in life before the day they became ill. I would like them to realize that we must give these young men unconditional love and support them in every way possible.

The **Chairman**. That is a very powerful note to end on.

I just have one or two questions for Michael. Do you have any contact now with your family?

Mr. **Sisco**. Just my oldest sister.

The **Chairman**. Are you able to work?

Mr. **Sisco**. No. I applied for Social Security and recently received it.

The **Chairman**. How do you pay your medical bills?

Mr. **Sisco**. I haven't been. I have a very good doctor in Charleston who tells me that that is the last thing I should worry about.

The **Chairman**. Well, that is a very good doctor.

Senator Harkin?

Senator **Harkin**. Mr. Chairman, I have a statement that I would like to enter into the record, and I cannot really add any questions at this time. I have listened to your questions, and I really have nothing to add.

The **Chairman**. I want to thank both of you for being here. I hope the Congress will have the courage you folks have exhibited and that all my colleagues will address this problem in a meaningful way and soon.

The legislation which we have reported unanimously by the Committee contains strong education provisions, such as the kinds of provisions you have called for today. It also provides for the kind of home care that you have described, Ms. Edwards. This is an important component in terms of home health care, and that is seen from the different programs that have taken place in California and other places, the importance and the significance as well as the cost saving aspects, and the other kinds of important qualities, not only in the medical services, but the caring for people.

We have other legislation which will deal with some of the discrimination which seems so prevalent these days. The only thing we are lacking is the coverage to deal with this kind of situation. I think the testimony here today will serve as a reminder of what needs to be done.

The problem, as you noted, Ms. Edwards, and as you have demonstrated, Michael, does not involve statistics. The problem we are talking about today involves human beings, human beings who are hurting and suffering and need our understanding and our compassion and help. I think we have to keep the pressure on, and we have to keep hearing from people like yourselves.

We are very grateful to both of you for your willingness to speak to us today with such frankness and candor. You make a very powerful, powerful case, and the ball is really in our court on this question. I just hope we are able to measure up to it.

I want to thank you both. If you want to keep in touch with us, we will be glad to let you know how the legislation is progressing. You have been a part of this whole legislative process, and you are certainly entitled. And if you have some ideas, Ms. Edwards, about whether there are some ways and means that we might be able to work something out through that legislation in terms of support groups like your own, I think we ought to instruct staff to see if something can be done on that as well.

Ms. EDWARDS. Thank you very much.

The CHAIRMAN. We will move now to the second panel. We now have the opportunity to hear from public health experts about the need for a comprehensive approach to halt the spread of the virus. In addition, each witness will explore the relative merits of more restrictive procedures which the Senate may be asked to consider.

We will hear first from Robert McAfee of the American Medical Association who will address their opposition to a Federally-mandated name reporting and contact tracing program, and we will then hear from James P. AuBuchon, the Chief Medical Officer of the American Red Cross, who will describe the various procedures they have put in place to maximize the safety of the blood supply. Finally, we will hear from Dr. June Osborn, Dean of the University of Michigan School of Public Health. She will discuss the importance of targeted information presented in a manner which reaches communities with a high incidence of the virus.

We very much appreciate all their work on the issue and their willingness to be here with us this morning.

Dr. McAfee?

## STATEMENTS OF DR. ROBERT E. McAFEE, BOARD OF TRUSTEES, AMERICAN MEDICAL ASSOCIATION, ACCOMPANIED BY MICHAEL ZARSKI, DIVISION OF LEGISLATIVE ACTIVITIES, AMA; DR. JAMES P. AUBUCHON, CHIEF MEDICAL OFFICER, AMERICAN RED CROSS MEDICAL OPERATIONS; AND DR. JUNE E. OSBORN, DEAN, SCHOOL OF PUBLIC HEALTH, UNIVERSITY OF MICHIGAN

Dr. McAFEE. Mr. Chairman, Senator Harkin, my name is Dr. Robert McAfee, and I am a physician in the practice of general surgery in Portland, Maine. I am also a member of the Board of Trustees of the American Medical Association. With me this morning is Michael Zarski, of the Association's Division of Legislative Activities.

Mr. Chairman, I would first like to share a small anecdote with you. It was roughly 30 years ago that I first met you when, as a third-year medical student in Boston, I was assigned the duty of drawing blood at New England Baptist Hospital.

The CHAIRMAN. Ah—I have been looking for you. Have you gotten rid of that dull needle? [Laughter.]

Dr. MCAFEE. On the contrary, Senator Kennedy. I remember very well the kind words you gave me about my dexterity and skill in drawing blood. In fact, you asked for me on several occasions when some of my colleagues could not achieve the same result. I find it very interesting that, 30 years later, we are sitting here again discussing a blood test.

The CHAIRMAN. Where do you practice presently?

Dr. MCAFEE. I practice medicine in Portland, Maine.

The CHAIRMAN. Are you affiliated with that medical center?

Dr. MCAFEE. Maine Medical Center in Portland, yes.

The CHAIRMAN. That is a terrific medical center, since you have mentioned it. I think, as a matter of fact, you have got probably one of the lowest infant mortalities of any medical facility in the country, as I remember.

Dr. MCAFEE. The Maine Medical Center, as well as the State of Maine itself, has a very low infant mortality rate. For many years we were number one in the country. We are now third or fourth.

The CHAIRMAN. Well, it is a wonderful indication of the work of the medical profession up there.

Dr. MCAFEE. Thank you, sir.

The AMA appreciates this opportunity to appear before the Committee and respond to your invitation to express our views on the appropriate Federal policy on the issues of reporting HIV-positive individuals and contact tracing.

There appears to be general recognition that action at the Federal level must be very carefully considered inasmuch as State and local jurisdictions need flexibility to develop policy that best fits their individual needs. With this in mind, the American Medical Association has analyzed the goals of reporting HIV-positive individuals and contact tracing. We have concluded that appropriate reporting and contact tracing could be a benefit to public health. But we also recognize that there are circumstances where the benefits to the public health afforded by certain reporting or contact tracing schemes may not outweigh the compromise to the rights of individuals.

We believe that local health officials would benefit from reports of HIV-seropositivity. For example, they can determine if testing programs are reaching a significant infected population. Accordingly, the AMA believes that individuals who are found to be seropositive to HIV should be reported to appropriate public health officials on an anonymous or confidential basis—and I emphasize on an anonymous and confidential basis—with enough information to be epidemiologically significant.

States may, in addressing their particular problems, require reporting by various methods. In any event, measures to provide confidentiality and protection against discrimination are essential to the success of any reporting program. Even with confidentiality and anti-discrimination safeguards in place, such reporting could deter some from seeking testing and counseling.

We therefore recommend a flexible approach, allowing for State and local options, that precludes a single Federal standard in this area.

One of the more difficult issues facing society is how to warn unsuspecting spouses or sexual partners of persons who test HIV-positive. Such a warning would allow the third party to take measures to avoid exposure. As a general rule, the AMA believes that unsuspecting contacts of a person who has been found to be infected with HIV should be informed of their risk. In some cases, it would not be responsible to rely on the infected individual to convey a suitable warning. Where intervention is indicated, public health officials and physicians should be able to act, and mechanisms analogous to those used in the past by public health authorities to warn contacts concerning sexually-transmitted disease should be utilized. We have experience in that endeavor.

The desirability of allocating limited resources to contact tracing will vary according to the population. Expenditures for contact tracing and resulting counseling and testing are aimed at a very narrow segment of the population. Such expenditures may actually be most effective in localities where the incidence of HIV infection is low and where those contacted would not otherwise know that they are at risk.

Those in the best position to determine whether to commit resources to contact tracing and the extent of those resources are at the State and local level. The Congress should not mandate this activity directly or as a strict condition for the receipt of Federal funds for essential HIV testing and counseling and general education programs.

Finally, Mr. Chairman, we would like to express our support for S. 1220, the Acquired Immunodeficiency Syndrome Research and Information Act of 1987. The comprehensive program contained in this bill, which has been reported by this Committee, will address critical needs for education, treatment and research on AIDS.

We also were privileged to testify before this Committee on S. 1575. We continue to support the testing, confidentiality, and anti-discrimination provisions that are included in S. 1575.

We commend you, Mr. Chairman, along with other sponsors and supporters of this legislation on the Committee for moving forward in this critical area. The AMA will continue with its AIDS-related activities directed toward the medical profession and the public. We hope to ensure that every physician in this country is aware of his or her need to maintain that very judicious balance between the rights of the individual patient being cared for maintaining the public health in this country.

The AMA Council on Ethical and Judicial Affairs recently addressed the issue of treating patients who test positive for the HIV antibody. The tradition of the AMA, since its establishment in 1847 has been that "when an epidemic prevails, a physician must continue his or her labors without regard to the risk of his own health."

Regarding AIDS, the Council has now stated that a physician may not ethically refuse to treat a patient whose condition is within the physician's current realm of competence solely because the patient is seropositive.

I would like to submit a copy of this ethical statement for the record, Mr. Chairman, and I would be pleased to answer any questions you may have.

The **Chairman**. We will be glad to receive that.

[Prepared statement of the American Medical Association follows:]

# STATEMENT

of the

AMERICAN MEDICAL ASSOCIATION

to the

Committee on Labor and Human Resources
United States Senate

Presented by

Robert E. McAfee M.D.

RE: AIDS Federal Policy—HIV Seropositivity
Reporting and Contact Tracing

November 18, 1987

Mr. Chairman and Members of the Committee:

My name is Robert E. McAfee, M.D., and I am a physician in the practice of surgery in Portland, Maine. I am also a member of the Board of Trustees of the American Medical Association. With me is Michael J. Zarski of the Association's Division of Legislative Activities.

The AMA appreciates this opportunity to appear before the Committee and respond to the invitation to express our views on the appropriate federal policy on the issues of reporting HIV-positive individuals and contact tracing.

The AMA has been very impressed with the efforts of the Congress to formulate appropriate federal policy to address the challenge of AIDS. There continues to be sharp divisions over specific approaches, but general recognition of the gravity of the situation we face.

There also appears to be general recognition that action at the federal level must be carefully considered inasmuch as state and local jurisdictions need flexibility to develop policy that best fits their individual needs. This flexibility would be lost if the federal government was to establish preemptive parameters. In addition, available federal and state resources are limited and should be put to maximum use for purposes best suited to their areas of jurisdiction.

As this disease has evolved in the United States, it has become apparent that we will be living with the threat of AIDS for a long time. In the United States, we already have had more than 43,000 confirmed cases of AIDS. More than half of those patients are now dead. And the disease shows no signs of abating. During the next four years, the number of confirmed cases in the U.S. is expected to climb to 323,000. At present, it is estimated that as many as two million Americans may be infected with the AIDS virus. The majority of these people do not know they are infected, and all have the potential of infecting others. Scientific evidence continues to accumulate that a high percentage, if not all, of those infected will develop the disease and face a fatal outcome.

Given the growing dimensions of the crisis and given limited national resources, it is imperative that a national policy be developed jointly by the public and private sectors. Such a policy must seek, in a cost-effective way, to achieve fundamental national goals: prevention, treatment, and cure--and adequate research in all three areas. A coherent national approach to this modern killer is needed--a comprehensive blueprint for a national response, not piecemeal solutions.

Such a national policy must have certain characteristics:

- The policy must be comprehensive, proceeding simultaneously on the fronts of prevention, treatment, and research.

- The policy must be coordinated between public and private sectors and between the different levels of government. A national policy does not necessarily mean a federal policy: there are important roles at all levels of the health care system and at all levels of government. Nor does it necessarily mean uniformity: on certain issues different approaches should be tried to determine efficacy.

- The policy must be carefully balanced. For example, concern for the person with the disease must be balanced with concern for those who do not have the disease but who may become infected. Similarly, careful consideration must be given to directing scarce resources to increased prevention, even as increasingly large resources are necessarily devoted to research and treatment.

- The policy must be based on scientific information and medical judgments. Although policy choices must inevitably be made, they should be formed on the best available information and on the extensive public health experience in dealing both with AIDS and with other contagious diseases.

- The policy should be nonpartisan. Although it may be tempting to play on fears and prejudices, public figures and officials both inside and outside the health community should avoid exploiting the crisis for partisan political advantage.

- The policy should be capable of continuous review and modification as more and better information becomes available.

With this in mind, the AMA has analyzed the goals of reporting HIV-positive individuals and contact tracing. We have concluded that appropriate reporting and contact tracing could be a benefit to public health. We also recognize that there are circumstances where the benefits to the public health afforded by certain reporting or contact tracing schemes may not outweigh the compromise to the rights of individuals. We, therefore, favor a flexible approach--allowing for state and local options--that precludes a single federal standard in this area.

We believe that local health officials would benefit from reports of HIV-seropositivity, for example, to determine if testing programs are reaching a significant infected population. Accordingly, the AMA believes that individuals who are found to be seropositive to HIV should be reported to appropriate public health officials on an anonymous or confidential basis, with enough information to be epidemiologically significant. States may, in addressing their particular problems, require reporting by name. In any event measures to provide confidentiality and protection against discrimination are essential to the success of any reporting program. Even with confidentiality and anti-discrimination safeguards in place, such reporting could deter some from seeking testing and counseling.

Another reason often advanced for reporting of HIV-positive individuals would be to collect data on the prevalence and spread of HIV. At the present time only those cases that meet the current CDC surveillance definition of AIDS are reported to that institution. Since AIDS is the final and to date, the uniformly fatal stage of HIV-infection, it presumably represents only the tip of the iceberg. How large the base of that iceberg really is--that is, how many people are actually infected--can only be estimated from the number of reported AIDS cases. The CDC itself is unsure about the accuracy of its estimates. Yet if sound economic and medical plans are to be made for the future, more reliable projections must be available.

Reporting of infected individuals who have come to light as a result of voluntary testing would not, however, provide an accurate reflection of the prevalence of infection in the population. The AMA has recommended a national study in various areas of the country to determine the prevalence and conversion rate of the HIV in the United States population. This study must be repeated at appropriate intervals to gauge the spread of the disease. This essential research effort is now underway by the CDC.

One of the more difficult issues facing society is how to warn unsuspecting spouses or sexual partners of persons who test HIV positive. Such a warning would allow the third party to take measures to avoid exposure. As a general rule, the AMA believes that unsuspecting contacts of a person who has been found to be infected with HIV should be informed of their risk. In some cases, it would not be responsible to rely on the infected individual to convey a suitable warning. Where intervention is indicated, public health officials should be able to act, and mechanisms analogous to those used in the past by public health authorities to warn contacts concerning sexually transmitted disease should be utilized.

The desirability of allocating limited resources to contact tracing will vary according to the population. Expenditures for contact tracing and resulting counseling and testing are aimed at a very narrow segment of the population. Such expenditures may be most effective in localities where the incidence of HIV infection is low and where those contacted would not otherwise know they are at risk.

On the other hand, in populations with a high incidence of infection and with many individuals practicing high-risk behaviors, resources may be more effectively directed toward voluntary testing of all high-risk individuals with education and counseling to eliminate behavior which leads to further transmission of the infection.

Those in the best position to determine whether to commit resources to contact tracing and the extent of those resources are at the state and local level. The Congress should not mandate this activity directly or as a strict condition for the receipt of federal funds for essential HIV testing and counseling and general education programs. Federal financial assistance, however, would undoubtedly be of great benefit to those contact tracing programs which have been initiated by the states.

Finally, we would like to express our support for S. 1220, the Acquired Immunodeficiency Syndrome Research and Information Act of 1987. The comprehensive program contained in this bill, which has been reported by this Committee, will address critical needs for education, treatment, and research on AIDS. We commend you, Mr. Chairman, along with other sponsors and supporters of this legislation on the Committee for moving forward in this critical area. We hope that the call for swift passage of this measure in the full Senate and in the House does not go unheeded.

The AMA, for our part, will continue with our AIDs-related activities directed toward the medical profession and the public.

Just to mention a very recent development, the AMA Council on Ethical and Judicial Affairs has addressed the issue of treating patients who test positive for the HIV antibody. The tradition of the AMA, since its organization in 1847, has been that "when an epidemic prevails, a physician must continue his [or her] labors without regard to the risk to his own health." Regarding AIDS, the Council has now stated that a physician may not ethically refuse to treat a patient whose condition is within the physician's current realm of competence solely because the patient is seropositive.

## Conclusion

Congress should not mandate universal reporting of HIV-positive individuals or contact tracing but should allow for state initiative in these areas. The federal government should stimulate the development of programs focusing on education and prevention of transmission, with financial assistance to encourage local programs for testing and counseling. The federal government continues to have a special role, of course, to provide for essential research.

The AMA is constantly reviewing its policies as our knowledge of AIDS develops. Modifications of our policies will be made as the scientific knowledge and information about the disease warrant. We would reiterate the caution that we expressed earlier that action at the federal level must be carefully considered.

Mr. Chairman, we would be pleased to answer any questions you may have.

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The **Chairman**. Just a few questions, Dr. McAfee.

As I understand it, historically, there has never been reporting of names to the Federal Government for any disease. Is that your understanding?

Dr. **McAfee**. Yes, sir.

The **Chairman**. So, the times we have been faced with other serious communicable disease, we have not, submitted the names for sound public health—public policy reasons. You record the incidence of the disease and whether it is progressing in various different areas, communities, or populations. But we have never required the submission of names, as I understand it.

Is that your understanding, too?

Dr. **McAfee**. Yes. We do have reporting to public health authorities at a local level for a variety of reasons.

The **Chairman**. All right. What would be the value from a public health point of view of reporting that information to the Federal Government? It really would not provide any information about the disease or its spread that we do not get from our current reporting system, would it?

Dr. **McAfee**. I think not.

The **Chairman**. And since the testing and education is done at the local level by the States or the private health care delivery system, reporting the names to the Federal Government would not really contribute anything that would enhance our efforts to stop the spread of AIDS, would it?

Dr. **McAfee**. I would agree.

The **Chairman**. And wouldn't you agree that an additional expense would be associated with such reporting, and although such reporting would have value in the battle against AIDS, do you also agree that it is not the wisest way to be spending limited resources?

Dr. **McAfee**. The cost of reporting and the cost of contact tracing would take a significant part of the very precious health care dollar we are now allocating to AIDS.

The **Chairman**. And you have also indicated support for important procedures to ensure confidentiality and protections against discrimination. Why do you feel anonymous reporting is so important?

Dr. **McAfee**. One must understand, Senator, that the populations we are dealing with are for the most part minority populations. They already feel a certain sense of discrimination in this country. We must identify those individuals who need counseling and education. To create a system which drives these individuals away from that arena of help would go totally against the concept of health care in this country.

I think for that reason, access to the testing mechanism and access to health care in general should not be barred by discriminatory policies that reflect badly upon the individual patient.

The **Chairman**. Just one more question, and that concerns contact tracing. It is my sense that this procedure is generally misunderstood, and in fact this Committee has been told it is more appropriately referred to as "partner notification." Can you explain the process and how it works?

Dr. McAFEE. Contact tracing is a process which has allowed us to control outbreaks of highly infectious disease. It has been the public health authorities' responsibility to identify the population and to provide treatment. We have had curative treatment for most of the other sexually-transmitted diseases available to us.

The problem with AIDS is the long lag time that we have. One may have had an exposure five years ago that has resulted in seropositivity without the individual being aware of it. In the absence of any curative treatment that would then allow a change in the outcome of that individual, we feel that spending some of those precious dollars, or a lot of those precious dollars, through a process of contact tracing would not be particularly rewarding. It is estimated that it might even cost upwards of $100 per contact to identify these individuals.

And we are not limiting this to sexual partners or spouses. We also have a substantial population of AIDS patients who are drug addicts, who share needles, who have a large number of other contacts, and this would obviously be an expensive way to identify that population.

The CHAIRMAN. Do you see any usefulness in implementing a forceful or detective type of tracing? Wouldn't such a notion drive those infected underground and ultimately make it more difficult to educate the infected and stop the spreading of the disease?

Dr. McAFEE. I think we must be very cautious we don't adopt a stance that would prevent those individuals from being helped.

The CHAIRMAN. We will go to Dr. AuBuchon, if you would be good enough to testify.

I would indicate to Senator Harkin that any time you wish to question, we will get an opportunity to talk to the members of the panel again, but we will move ahead.

Dr. AUBUCHON. Mr. Chairman, Senator Harkin, I am Dr. James AuBuchon, Medical Officer, Medical Operations, American Red Cross.

I am pleased to have been asked to discuss with you steps that the American Red Cross has taken to make the blood supply safe. Additional information regarding protective measures for AIDS and other diseases such as hepatitis can be found in my written testimony.

AIDS is certainly the greatest infectious disease concern of the patient about to receive a blood transfusion. Prevention of the spread of the cause of AIDS, the human immunodeficiency virus, or HIV, through blood transfusion, involves many different procedures that combine to provide a high degree of protection.

The cornerstone of this protection is education and self-deferral of donors at increased risk of HIV infection. Activities that may have placed a prospective donor at risk for exposure to HIV are clearly spelled out in a pamphlet read by all donors before donation. Those potential donors, who have signs or symptoms of AIDS, or who may have placed themselves at risk of contracting HIV, are told they must not donate blood.

A further opportunity to defer donors at risk for transmitting HIV occurs when a trained Red Cross nurse reviews the prospective donors' health history in a confidential interview. The nurse asks specific questions about signs and symptoms that might be referable to AIDS or HIV infection. The nurse also asks about the general health of the donor, past signs and symptoms of other communicable diseases such as hepatitis, and activities such as intravenous drug use that may have led to exposure of the individual to HIV or other infectious diseases.

At the end of this interview, the prospective donor signs a statement verifying that he or she has read the information regarding the modes of spread of HIV and agrees not to donate blood for transfusion if he or she is at risk for having been exposed to HIV.

The nurse also examines the arms of the donor for evidence of needle marks indicative of intravenous drug use.

Two additional opportunities are available to the donor to identify his or her blood donation as one that should not be transfused to a patient. The first of these is called the confidential unit exclusion procedure. In this step, the donor reads another reminder of the importance of truthful health and exposure histories, and a listing of those individuals who must not give blood is reiterated.

The donor then checks one of two boxes—yes, my blood may be used for transfusion, or no, my blood should not be used for transfusion. This ballot is identified only by the number on the unit of blood, not the donor's name. Should the donor not recognize his or her risks, or decide not to identify the donation as potentially at risk for transmitting HIV until after leaving the donation site, the donor can refer to a take-home card given each donor with the number of their donation. This card urges that such donors contact the blood center by phone.

Testing for the presence of HIV antibodies and all blood donations is another important step in maintaining a safe blood supply. Test procedures are performed with reagents licensed by the Food and Drug Administration. In addition to approval of each of these lots of reagents by the FDA, the American Red Cross has established an additional panel of blood samples that is used to test each lot of reagents before release for use in the Red Cross system. These reagent verifications, plus routine quality control procedures and laboratory proficiency checks afford assurance that the reagents and procedures in use for HIV testing represent the highest level of sensitivity to HIV antibodies.

Over 2,000 blood donors have been notified by the American Red Cross that their blood was found to contain antibodies to HIV. On notifying these individuals, none have been found to have donated out of malicious intent or previously knew themselves to be HIV-positive. Instead, these individuals either did not understand that past activities had placed them at risk for HIV infection or psychologically were not able to recognize that the list of individuals who must not give blood applied to their situation.

Therefore, we do not believe that criminalization of donation from HIV-positive individuals would add any safety to the blood supply. Instead, such a statute might have a chilling effect on the altruistic motivation of volunteer blood donors.

Before any unit is released to a hospital from a Red Cross blood center, the past donation record of the donor is checked. The Red Cross maintains a confidential registry of donors previously found to have positive test results in infectious disease tests donors who gave histories that would prevent their future donations and donors whose previous blood donations resulted in the transmission of an infectious disease to the recipient of the donation.

The commitment of the Red Cross to safety in transfusion medicine does not end with the delivery of the unit of blood to the hospital. The American Red Cross is active in many other programs to enhance the safety of transfusion medicine.

Much attention has been given in the media lately to HTLV-I. This virus is in the same family as HIV and appears to be transmitted in the same manner. Individuals infected with HTLV-I may develop a fulminant type of leukemia or a disorder of their central nervous system that leads to loss of muscle control, after a latent period of years, or decades.

HTLV-I is very rare in this country, but is more prevalent in southern Japan and certain parts of the Caribbean. The Red Cross has recognized the potential for harm to recipients of blood that this virus may pose and is taking steps to prevent the spread of the virus.

Implementation of testing will require FDA licensing of a reproducible test that detects antibodies to HTLV-I. The Red Cross has pledged its assistance to the FDA in gathering samples needed to use in the licensure process.

I must stress that these actions are being taken in advance of knowledge of any transfusion-transmitted clinical disease due to HTLV-I in order to prevent this virus from being transmitted to recipients of blood transfusions.

For some blood products, additional protective measures may be taken after donor screening and blood testing. Special viral inactivation procedures can be utilized to prevent or greatly reduce the likelihood of transmission of viruses through plasma derivatives.

The American Red Cross is also actively involved in several research projects to develop means of inactivating or removing viruses from liquid blood products.

The American Red Cross has also established a surveillance system to detect new potential threats to the blood supply in the form of new viruses appearing in donors.

The Red Cross is also sharing information with the Centers for Disease Control in order to better understand infectious disease risks in the general population.

Although many steps and procedures have been added to make the blood supply safe, any set of safeguards is not foolproof. Physicians and patients should understand that although the blood supply is safe, it is not perfect. Therefore the American Red Cross is actively engaged in promoting alternatives to standard forms of transfusion therapy in order to minimize any risk to patients who might be in need of a transfusion.

In summary, the commitment of the American Red Cross to a safe blood supply is demonstrated through the many different safeguards taken in donor education, selection and testing, as well as through ventures in research, professional education and program and product development. The American Red Cross realizes that this diligence must be maintained through refinement of current techniques and development of new ones in order that the therapeutic goals of modern medical care can be achieved.

The staff and volunteer leadership of the American Red Cross remain committed to provision of a safety and adequate blood supply.

Thank you.

Senator **Weicker** [presiding]. Thank you very much, Dr. AuBuchon.

[The prepared statement of Dr. AuBuchon follows:]

TESTIMONY OF

James P. AuBuchon, MD
Medical Officer
Medical Operations
American Red Cross

before the
Labor and Human Resources Committee
of the
United States Senate

The Honorable Edward M. Kennedy, Chairman

## Introduction

Modern medical practice requires safe and efficacious blood products. The American Red Cross -- its staff of dedicated nurses, medical technologists, physicians and other professionals, and its volunteer leadership -- are committed to ensuring that the best in medical care can be delivered to patients by providing an adequate supply of safe blood products. I would like to review with you the steps the American Red Cross has taken to secure the safety of the blood supply.

## Specific Measures - By Disease

### Acquired Immune Deficiency Syndrome

AIDS is certainly the greatest infectious disease concern of a patient about to receive a blood transfusion. Prevention of the spread of the cause of AIDS, the human immunodeficiency virus - HIV, through blood transfusion involves many different procedures that combine to provide a high degree of protection against this potential for transmission.

#### Education and Self-Deferral

The cornerstone of these safety efforts rests with education of potential donors so that they recognize whether they may have themselves been exposed to HIV. Activities that may have placed a prospective donor at risk for exposure to HIV are clearly spelled out in a pamphlet read by all donors before donation. Those potential donors who have signs or symptoms of AIDS or who may have placed themselves at risk of contracting HIV are told they must not donate blood. They may leave the donation site without explanation in order to preserve their confidentiality.

### *Confidential Health History*

A further opportunity to defer donors at risk for transmitting HIV through a blood donation occurs when a trained Red Cross nurse reviews the prospective donor's health history in a confidential interview. The nurse asks specific questions about signs and symptoms that might be referable to AIDS or HIV infection. The nurse also asks about the general health of the donor, past signs and symptoms of other communicable diseases, such as hepatitis, and activities, such as intravenous drug abuse, that may have led to exposure of the individual to HIV or other infectious diseases. At the end of this interview, the prospective donor signs a statement verifying that he or she has read the information regarding the modes of spread of HIV and agrees not to donate blood for transfusion if he or she is at risk for having been exposed to HIV.

### *Physical Examination*

During a brief physical examination that includes checking the donor's pulse, blood pressure, temperature and hemoglobin concentration, the nurse examines the arms of the donor for evidence of needle marks indicative of intravenous drug use.

### *Confidential Unit Exclusion and Callback Procedures*

There is a potential that peer pressure or other concerns may prevent a prospective donor who is at risk for having been exposed to HIV from leaving the donor site or being truthful in his or her responses during the interview. If this is the case, two additional opportunities are available to the donor to identify his or her blood donation as one that should not be released for transfusion. The first of these is called the Confidential Unit Exclusion Procedure; in this step, the donor reads another reminder of the importance of truthful health and exposure histories, and a listing of those individuals who must not give blood is reiterated. The donor then checks one of two boxes: Yes, my blood may be used for transfusion, or No, my blood should not be used for transfusion. This "ballot" is marked only with the number on the unit of blood, not the donor's name. It is sealed and deposited in a closed box. Should the donor not recognize his or her risks or decide not to identify the donation as potentially at risk for transmitting HIV until after leaving the donation site, the donor can refer to a take-home card given each donor with the number of their donation. This card urges that such donors contact the blood center by phone; by giving only the number of their donation and the statement that it should not be used for transfusion, the donation can be removed from distribution.

HIV Antibody Testing

Testing for presence of HIV antibodies in all blood donations is another important step in maintaining a safe blood supply. Test procedures are performed with reagents licensed by the Food and Drug Administration and are used according to the manufacturer's directions. In addition to approval of each lot of reagents by the FDA, the American Red Cross has established an additional panel of blood samples that is used to test each lot of reagents before release for use in the Red Cross system. These reagent verifications, plus routine quality control procedures and laboratory proficiency checks, afford us assurance that the reagents and procedures in use for HIV testing represent the highest level of sensitivity to the HIV antibodies.

(It should be noted that the initial test used on donated blood is extremely sensitive but not entirely specific, that is, it generates false positive results. Although donors with false positive results are not notified of this, inasmuch as scientific evidence has shown that these donors are not truly infected with HIV, only the blood that tests entirely negative in this very sensitive test is released to hospitals for transfusion.)

Deferred Donor Registry

Before any unit is released to a hospital from a Red Cross blood center, the past donation record of the donor is checked. The Red Cross maintains a confidential registry of donors previously found to have positive test results in infectious disease tests, donors who gave histories that would prevent their future donations and donors whose previous blood donations resulted in the transmission of an infectious disease to the recipient of the donation. Such donors are notified that they are not eligible to donate and are instructed not to donate again. However, in the unlikely event such a donor should return and fail to give the same history or test as positive again, use of this registry would interdict the unit of blood and prevent its release to a hospital.

Lookback and Recipient Testing

The American Red Cross has been involved, along with other blood collecting organizations and hospitals, in a program to identify and notify recipients of blood that may have contained HIV. After testing for HIV antibodies began, some donors have been identified as HIV-positive who donated prior to availability of the test. Prior donations are tracked to hospitals and, ultimately, to recipients, who are then advised of the situation and encouraged to be tested for HIV and recognize risks for subsequent transmission of the virus should they have been infected.

Similarly, the Centers for Disease Control has recommended that patients who received blood transfusions prior to the advent of HIV testing discuss their being tested with their own physician. While the risk of transmission was low, the CDC advised that it may be prudent to consider testing of recipients in certain circumstances. Red Cross blood centers have assisted in this effort by providing laboratory testing services or, in some communities, testing and counseling services.

## Hepatitis B

The same measures applied to increase the safety of the blood supply with respect to HIV also apply to safety from transmission of hepatitis B (serum hepatitis). These two viruses are transmitted in similar ways and are more prevalent in the same groups of individuals. Therefore, the steps outlined above are also effective in reducing the risk of the hepatitis B virus being transmitted through a blood product. All donations are tested for the presence of the hepatitis B virus in order to detect carriers of this disease.

## Non-A, Non-B Hepatitis

Non-A, non-B hepatitis (NANB) is caused by several viruses that can be transmitted by blood and other routes. Once thought to cause a self-limited, innocuous form of liver inflammation, recent studies have indicated that NANB may cause serious, long-term liver disease. Once this information was known, the American Red Cross moved quickly to begin testing to reduce the risk of transmission of this disease through blood transfusion.

The viruses that cause NANB have never been isolated, however, and no specific tests for them have been produced. (This is unlike the situation with hepatitis B where laboratories can test blood directly for the presence of the hepatitis B virus.) Instead, the Red Cross uses two "surrogate" tests to identify donors who may be at higher risk of transmission of NANB. Retrospective studies have shown that donors who have elevations in their blood of an enzyme produced in their liver (alanine aminotransferase - ALT) are more likely to transmit NANB to recipients of their blood donations. Similar studies have shown that donors who have been exposed to hepatitis B and have an antibody against a protein in its core ("core antibody" - anti-HBc) also are at a higher risk of transmitting NANB through a blood donation. (The reason for this association is not known.)

Unfortunately, these surrogate tests have poor sensitivity and specificity: They fail to detect all donations capable of transmitting NANB and find as unacceptable for transfusion blood from donors who have donated many gallons of blood without any infectious complications in the recipients. Consequently, the Red Cross must collect an additional 5% of blood because of test losses due to ALT and anti-HBc and must deal with dedicated donors whose blood is now found unacceptable for transfusion. The Red Cross believes, however, that these steps are important additions to the steps used to assure the safety of the blood supply.

## Syphilis

All donations are tested for syphilis. Although the bacterium that causes syphilis does not survive under standard blood storage conditions, this test remains a test required by the FDA of all licensed blood banks to assure that syphilis is not transmitted by blood.

## Cytomegalovirus

Almost all transfusion recipients are susceptible to the disease discussed above. However, other diseases may be a problem only for certain recipients. An example of this is cytomegalovirus (CMV). Most Americans are exposed to this virus at some time in their life, and few have any clinical symptoms from an infection. In a patient whose immune system is less able to fight the infection, however, CMV may cause severe or life-threatening illness. Underweight, premature infants may suffer severe pneumonia, anemia and hepatitis from CMV infection. A major cause of death in bone marrow transplant recipients has been CMV infection. For those patients whose physicians believe that CMV represents a disease risk, Red Cross blood centers provide blood that has been tested for CMV. Similar to the test for HIV in that it detects antibodies to the virus and thus a potential for infectivity, the CMV test can help prevent a very significant infection for those patients in whom it could be a concern. Other Red Cross blood centers provide frozen, thawed and washed red cells for transfusion to patients needing to avoid CMV. This technique removes white cells from the red cell unit; since CMV is transmitted through white cells, this approach also prevents CMV infection.

## HTLV-I

Much attention has been given in the media lately to

HTLV-I. This virus is in the same family as HIV and appears to be transmitted in the same manner. Individuals infected with HTLV-I may develop a fulminant type of leukemia (adult T-cell leukemia - ATL) or a disorder of their central nervous system that results in loss of muscle control (tropical spastic paraparesis - TSP) after a latent period of years or decades. HTLV-I is very rare in this country but is more prevalent in southern Japan and certain parts of the Caribbean.

The Red Cross has recognized the potential for harm to recipients that this virus may pose and is taking steps to interdict any spread of the virus. Japanese studies have indicated that HTLV-I may be transmitted through blood transfusion, but, to date, no cases of ATL or TSP have been linked to blood transfusion. A large study conducted by the Red Cross, soon to be published in a scientific journal, has led us to the conclusion that it would be prudent to test blood donations for past exposure to this virus. Implementation of testing will require FDA licensing of a reproducible test that detects antibodies to HTLV-I. The Red Cross has pledged its assistance to the FDA in gathering samples needed to investigate manufacturers' tests submitted for licensure.

The Red Cross stresses that these actions are being taken in advance of knowledge of any transfusion transmitted clinical disease in order to prevent HTLV-I from being transmitted to recipients of blood transfusions.

## Special Measures - Plasma Derivatives

Special viral inactivation procedures can be utilized to prevent or greatly reduce the likelihood of transmission of viruses through plasma derivatives. Plasma derivatives are biological products derived from blood that are concentrated forms of one or a group of specialized proteins normally found in plasma. For example, albumin can be separated from plasma and used to treat patients needing expansion of their blood volume. Because albumin can be treated at 60C for 10 hours, no viruses are transmitted through it. Similar techniques have been applied more recently to other products to reduce their potential infectivity.

Heat has been used to inactivate HIV in antihemophilic factor concentrates used to treat hemophiliacs. Although heating lyophilized (final product) derivatives is not able to inactivate hepatitis B and NANB viruses while retaining potency of the final product, newer methods of viral inactivation appear to be more successful in eliminating these viral threats. Heating the product while it is still in a liquid state (before lyophilization) and treatment of the derivative product with an extractable chemical solvent that removes the lipid coat from viruses appear to be effective forms of preventing transmission of not only HIV but also hepatitis B and NANB. Purification techniques utilizing monoclonal antibodies, also appear to produce protein derivatives with greatly reduced potential for viral infectivity, potential that can be reduced further through use of viral inactivation procedures.

## Research and Development

The American Red Cross is actively involved in several research projects to maintain and advance the current level of blood supply safety and to develop means of inactivating or removing viruses from liquid blood products as they have been inactivated in several plasma derivatives.

The Red Cross has several research projects underway designed to enhance the safety of the blood supply through better understanding of donors. A surveillance system has been established to detect new potential threats to the blood supply through new viruses appearing in donors. The Red Cross is also sharing information with the Centers for Disease Control in order to better understand infectious disease risks in the population.

A major thrust of research and development for the Red Cross is in the field of viral depletion and inactivation in liquid blood products. Inasmuch as cellular blood products, such as units of red cells or platelets, contain living cells, these blood products cannot be treated in the same manner as protein derivatives in order to inactivate any viruses they might contain. The Red Cross has initiated multiple projects to develop means to augment the screening and testing detailed above with another line of defense to maintain the safety of the blood supply.

## Promotion of Transfusion Alternatives

Although many steps and procedures have been added to make the blood supply safe, any set of safeguards is not foolproof. Physicians and patients should understand that, although the blood supply is safe, it is not perfect. Therefore, the American Red Cross is actively engaged in promoting alternatives to standard forms of transfusion therapy in order to minimize any risk to patients who might be in need of a transfusion.

### Physician Education

Specialists in transfusion medicine cite data indicating that transfusions have been prescribed in inappropriate circumstances in the past. The American Red Cross is using its regional medical staff, its researchers and its public position to impress upon physicians that transfusions should be given only when necessary to achieve specific, required clinical outcomes. When a transfusion is necessary, the Red Cross takes the position that all alternatives should be considered, beginning with the safest product or treatment. In order to maximize patient safety, programs have been implemented in Red Cross blood centers to ensure that these alternatives are available to physicians and patients.

## Autologous Transfusion

Most important among these alternatives is autologous transfusion, the patient being his own donor. The Red Cross has revised its programs for pre-operative autologous donation to increase accessibility to the service. The volume of units donated for autologous use has tripled in the last year, and it is anticipated that within the next 18 months, at least ten percent of blood collected by the American Red Cross will be autologous in origin.

In addition to learning more about the needs of patients and physicians and ensuring that pre-operative autologous donation programs are available to meet those needs, the American Red Cross has begun provision of intra-operative blood salvage services. Intra-operative blood salvage allows the recovery, purification and reinfusion of blood shed into an operative wound, thus reducing the need for transfusion using blood from donors. This service requires a trained staff and sophisticated equipment beyond the resources of most small and medium-sized hospitals. By offering this service on a regional basis, Red Cross blood centers can serve the needs of a community and reduce the transfusion requirements of surgery and trauma patients.

## Directed Donations

Directed donations are units of blood from donors recruited by the patient. The concept of directed donations, that the patient is better able to select "safe" donors than the traditional blood recruitment system, has not been supported by studies published to date. Nevertheless, the psychological benefits from having selected one's blood donors may considerable. Red Cross blood centers are offering this service along with safeguards, such as the Confidential Unit Exclusion Procedure, to prevent undue coercion of donors who should not be donating blood.

## "Single Donor" Products

Many blood products must be transfused in large quantities in order to be clinically effective. For example, platelets must be given in a number equivalent to the amount obtainable from six to ten whole blood units in order to have a therapeutic effect. Transfusion support thus involves exposure to the blood of many donors. To reduce the risk of exposure to infectious agents and to the blood cells of donors that may incite an immune response that may lead to "rejection" of future transfusions, many clinicians now believe that it may be advantageous to use a therapeutic dosage of a blood component derived from a single donor.

Red Cross blood centers are moving to provide increased numbers of "single donor" products, such as platelets. Instead of deriving the platelets from several whole blood units for transfusion to a patient, a donor is recruited to undergo a special platelet recovery procedure that yields a therapeutic dose of platelets. This procedure requires additional time and inconvenience on the donor's part and additional staff and equipment in the blood center, but the result is a product that may have a reduced potential for transmission of an infectious agent.

## Summary

The commitment of the American Red Cross to a safe blood supply is demonstrated through the multifaceted safeguards taken in donor education, selection, and testing as well as through ventures in research, professional education and development. The American Red Cross realizes that this diligence must be maintained through refinement of current techniques and development of new ones. The staff and volunteers of the the American Red Cross remain committed to provision of a safe and adequate blood supply.

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Senator **WEICKER** [presiding]. Next, we have Dr. June Osborn, Dean of the School of Public Health at the University of Michigan.

Dr. Osborn?

Dr. **OSBORN**. Thank you. I am very pleased to have the chance to speak today.

I am a virologist and a pediatrician by background, and I am Dean of the School of Public Health at the University of Michigan and have been involved in a variety of advisory and educational roles with respect to the AIDS epidemic.

Education is our only weapon in the struggle to halt the spread of the virus of AIDS. While drugs such as AZT provide an important glimmer of hope for those already infected, vaccines or cures are many years off, and we cannot afford to wait. But thanks to extraordinary scientific progress, we already know what we need to know in order to design educational strategies for prevention of the further spread of the virus of AIDS.

If people are well-informed about the few ways in which that virus can be spread, most of them need not be fearful. Those persons whose behavior might put them at risk can be alerted and can decide to avoid this virus through personal decisionmaking about private consensual behavior. That is the path to the control of the epidemic, and there will never be a better vaccine than that.

However, we must act quickly to educate people at risk. The enemy in this war is a crafty, deadly virus, capable of staying quietly dormant, yet transmissible, for several years before AIDS develops. But it can only be spread by sexual intercourse, by sharing of illicit drug injection apparatus, by injection of large amounts of blood, or by birth. This makes behavior change the prime focus of our public health strategy now that screening of the blood supply is in place. And we must have people's focused attention as we educate to achieve that behavior change.

Our educational initiative has several goals. First, we must communicate convincingly to the general public about what does and does not cause spread of the virus of AIDS, for diffuse fear is our worst enemy. Unwarranted public fear is presenting serious problems at present, for it distorts efforts at the design of wise public policies. What is more, personal fear is incompatible with compassion, of which we have great need in the design of such policies and in our societal response, for the AIDS epidemic has already compiled a terrible anthology of tragedies.

In this effort we should be using clearly-worded messages and deploying all available media. Strong central leadership is essential to the credibility of such communication, and from the eery silence at the very top of our national effort to date, much fear and uncertainty has flourished and festered.

As a second educational goal, we must communicate to persons whose behavior may have put them at high risk. Our message to them must be plainly stated so that they can recognize their risk, and our programs must be designed to encourage them to step forward in confidential or anonymous circumstances to learn of their status, with counseling both to interpret antibody test results and to help prevent further risk behavior.

Third, we must educate adolescents and children about the new virus and its ways, for the world has changed forever with the arrival of AIDS, and it will be with us for generations to come. We cannot change that fact of life no matter what we do, but we can influence just how dominant a force it will be in the lives of our children's children by what we do now in the way of education for prevention.

Specific persons and groups at risk require specially targeted messages. While general and tasteful language can accomplish the goals of a national educational campaign, and while monogamy or chastity and abstinence from substance abuse can and could be described as the safest and most desirable decisions to be made about personal behavior, that does not suffice. We have fostered the most strikingly pluralistic society in history, and we have fought wars in the name of individual worth.

AIDS is so desperate a threat that we must not leave gaping holes in our defense effort by declaring certain strategies to be off limits, if they necessitate the acknowledgement of lifestyles and choices that depart from a defined norm.

Early in the epidemic we made some mistakes in trying to communicate through circumspection. For instance, we talked about "intimate contact" when we meant sexual intercourse, leaving loving families uneasy about affectionate non-sexual contact. And we talked about "exchange of bodily fluids" when we meant semen and cervical secretions, leaving people unnecessarily frightened about sweaty handshakes or restaurant utensils.

We have learned from those mistakes. We must speak in the languages of our intended listeners if we wish to be understood. That means that for specific communities and subcultures, the message must vary and must sometimes be quite explicit. That will present some difficult challenges, but to do less is to condone a virtual death sentence for unapproved behavior.

The Helms amendment therefore cripples our public health war effort in the most dangerous possible way. To take away the capacity of those on the front lines of prevention to deploy whatever tactical weapons they need is to condemn whole subsets of our society to a dreadful and unnecessary risk; and to forbid community organizations even to seek alternative funding to meet their needs without activating Federal funding sanctions is to paralyze them in the midst of the battle.

The price for such paralysis is unthinkable and will be paid by us all—both the direct cost of more of our citizens infected through lack of warning and the indirect cost inherent in the destructive effect on a society that puts some of its members beyond help.

Instead of such crippling maneuvers, it is time to embrace with all our energy and ingenuity the historically unique opportunity to interrupt a plague by education for prevention.

Thank you.

Senator WEICKER. Dr. Osborn, thank you very much.

First, let me ask a few questions of the witness from the Red Cross.

You have undoubtedly heard of proposals to criminalize the donation of blood by infected individuals. Can you tell us what effect this would have on our blood banking system? And here, I am not speaking of the person who knowingly and intentionally donates blood when they understand their blood may be dangerous to others. I believe I can speak for all of us in saying that that is clearly wrong. But I am speaking of proposals that would make it a criminal offense to donate blood if one were infected, if one were homosexual, if one came from an African country, or if one had sexual contact with someone who was infected. What would be the effect of such proposals?

Dr. AuBuchon. Blood bankers have two primary concerns. One is safety of the blood supply; the other is adequacy of the blood supply. I do not believe that such a criminalization statute would add in any way to the safety of the blood supply. As I detailed, we have a number of steps which are intended to allow individuals to identify themselves, to understand that they have placed themselves at risk for HIV exposure, and that they must not donate blood. These are effective in and of themselves.

As a second backup, we have the HIV antibody test, which is an extremely sensitive test. Together, these donor education and deferral procedures and the laboratory testing procedures provide a safe blood supply. I do not believe that the additional motivation that criminalization might be intended to provide would be successful in having individuals at risk for HIV exposure recognize the danger they might pose by donating blood.

Those individuals who are found to be HIV-positive after blood donation seem to have had difficulty recognizing that they placed themselves at risk in the first place; I do not believe a criminal statute would add anything to that.

The second concern of a blood banker is adequacy of the blood supply. Our donors are volunteer donors. They are motivated out of altruistic concerns for their community. If they had hanging over their heads a concern that if they were found HIV-positive through means that they would not have any way of recognizing ahead of time, and if they had concerns that, were they found to be HIV-positive, they might be facing a criminal charge, I think that would have a chilling effect on their willingness to roll up their sleeves and help their neighbors.

Therefore, I think that such a statute might have an adverse effect on the adequacy of the blood supply without increasing its safety.

Senator Weicker. I understand there is already a tremendous misunderstanding in the community about the supposed dangers of donating blood. Many people believe that donating blood puts you at risk of getting AIDS. If donating blood became a criminal offense, it seems to me this would be even more damaging to our efforts to increase the blood supply. And I gather from your remarks here that you would agree with that statement.

Dr. AuBuchon. I would. There have been a number of national studies asking just that question—what is the safety of donating blood—and anywhere from 15 to 40 percent of the general population still believes that they can come in contact with HIV through donating blood.

As you know, all of the needles that are used are used only one time, and they are pre-sterilized by the manufacturer, and there is absolutely no risk of coming down with any infectious disease from donating blood.

Nevertheless, we face an uphill recruitment battle in trying to educate prospective donors that donation is entirely safe.

We have experienced this year a 2 percent decline in donations to the American Red Cross. This has made it a difficult job for us to supply an adequate blood supply at all times in all parts of the country, and we are working to correct that, but we have a public education hurdle to overcome.

Senator **WEICKER**. And lastly, in reference to those individuals who knowingly donate blood and bypass all the opportunities to protect others, understanding full well that they may be harming others, is it your understanding that there are already criminal laws in every State which would allow authorities to pursue such a dangerous individual?

Dr. **AUBUCHON**. I am not aware of all State statutes in that regard. Certainly, we would hope that individuals would not display any malicious intent, and we have no evidence that any of our volunteer donors have displayed any malicious intent in donating blood. These individuals did not know they were HIV-positive when they came to donate.

Senator **WEICKER**. Senator Kennedy has informed me that this apparently is an area that the Judiciary Committee Chairman Senator Biden has committed himself to exploring, so whatever holes there are in the legal fabric, those will be tended to immediately.

I have seen a whole variety of AIDS information pamphlets published by the American Red Cross—i.e., "AIDS and Children for Parents and Teachers"; "Gay and Bisexual Men and AIDS"; "AIDS in your Job"; "AIDS, Sex and You".

How have you distributed these pamphlets, and how important do you feel it is to target specific populations of children, gay and bisexual men, intravenous drug users, with explicit explanations of how the virus is transmitted and may be prevented?

Dr. **AUBUCHON**. The majority of educational information produced by the American Red Cross, whether it is in the form of pamphlets or one of the two movies that we have made on the subject, are distributed locally through each one of the 3,000 Red Cross Chapters across the country. The positioning of these pamphlets or films depends on the local community and the need of the community.

If one is interested in stopping any hysteria about AIDS, undue concern about transmission through casual contact, for example, distribution is then usually through channels directed at the general population.

In some communities, particularly those with large at-risk populations, large groups of individuals who do engage in activities that may place them at high risk for HIV infection, the distribution is more targeted. Many of our Red Cross Chapters are active participants in local AIDS task forces that deal with educational needs of specific high-risk groups.

Senator **WEICKER**. Dr. Osborn, I was delighted to listen to your testimony and specifically that portion of your testimony that deals with the aspect that specific communities and subcultures require different messages.

Not only did I have to contend with the Helms language on the Floor—and I might add, if you think what we ended up with is bad, you should have seen what we started off with; and I agree both are bad—but indeed, in the AIDS legislation itself, which right now is awaiting Floor action, there has been a reticence to in effect require explicit education of our schoolchildren, never mind any subculture, but of our schoolchildren.

I would like you to just spend a few minutes and reinforce your former remark as to how important it is that we do not indulge ourselves in sensitivities, if you will, which in effect could result in the death—needless death—of others. And I suppose what bothers me here, and I think people have got to be made to understand this, is that there is no second chance. You cannot come around and say, "Oh, gosh, I wish I had this." If we could gradually educate, that would be a wonderful thing, I am sure you would agree. But there is no such thing as a gradual education here. It seems to me it is either a total education or indeed, you run the risk of needless death.

I would like you to comment upon that.

Dr. Osborn. I am pleased to have the opportunity to comment, and parenthetically, comment about my admiration for your courage with respect to the Helms amendment because these are very difficult things to deal with.

I find it easiest myself to get revved up about adolescents and children, and perhaps for the moment it is wise to focus on that in the context of the second chance, because much of the restrictive kinds of thinking that have dominated thus far in a relative nonresponse to the epidemic are in regard to established lifestyles, established groups within society, or at least perceived groups within society. And I think perhaps one of the fundamental definitions of adolescence is experimentation. There are many, many adolescents who have an experience or a few experiences en route to choosing a lifestyle that may be exemplary and may be indeed what others would like them to choose, but along the way have taken, characteristically some chances—perhaps even someone in this room has as an adolescent—and survived to tell about it or, more commonly, not to tell about it, later.

I think that now it is terribly important for parents to recognize and for adolescents themselves to recognize that this is a different kind of risk, as you say; that, for instance, the kid who goes and spends a weekend in Manhattan somehow and gets into the environs of somebody who is shooting up drugs, that did not normally condemn that kid to a life of drug abuse. That was an experiment that might be survived. But at the moment, the chances of that youngster sharing injection apparatus with an infected individual are better than 60 percent.

We have laws in the Manhattan area that make it impossible to get injection apparatus. I do not say that a kid should be able to get it, but I say that we have got a reality situation now that commands that we be very clear in our language. We are not talking about things that we characteristically giggled about, about gonorrhea, or something you can fix with penicillin.

And as somebody put it to me who is in the mid-path, this is like playing a game of Russian roulette that you lose, but it takes eight or sometimes ten years for the bullet to hit. So that people in fact can have gone through the maturation and become adults with a lifestyle and a trained talent and creativity that is terribly valuable and in fact precious to society, and then discover that in fact their earlier behavior had condemned them.

So the urgency of need for this kind of education is difficult to overstate for adolescents and for children. For targeted education for risk groups, I find astonishing the extent, the virulence, of homophobia and of some of the other hatreds that are coming to the fore in our discussions about AIDS. People may or may not approve, but do they really want to give a death sentence? Because that is what we are talking about now. If we do not educate people to the risk of becoming infected through certain defined, definable, and preventable behavior patterns, we are in fact passively allowing them to drive themselves over a very long cliff, as it were, with an awfully delayed outcome.

Any way you look at it, the cost to society is intolerable; the cost in terms of talented and trained individuals is intolerable. Now I think we are beginning to have a very common story of people who had engaged in lifestyles that some would not approve of and decided three or four years ago that they should not do that, that there was something dangerous, and then changed; many people adopted, for instance, a pattern of chastity or very strict monogamy and yet discovered they had been caught three or four years ago.

We are going to see tragedies that would make Aeschylus turn pale in the next few years and we are not going to be influencing much about what happens to those other than through compassionate care, which we must attend to. Our preventive efforts are for five and more years from now, and that is what adds to the sense of urgency; that what we do now is even worse political trouble than the language, because what we do now will not pay off in the next few years; it will pay off beyond that. And that is what I mean by saying it is our children's children and the extent to which their lives are dominated by this new human plague that we have to work at now. And that makes it, I guess, the worst possible problem for public policy, because the effectiveness of what we want to do is so delayed.

I should say, however, that we can already see glimmerings of the effectiveness of health education in some of the established ongoing studies of people who are in so-called high-risk groups. And there has been an absolutely dramatic downturn in the acquisition of infection in groups that have been organized but have been giving self-education at the community-based level; virtually no new sero-conversions in one group that has been followed longitudinally in San Francisco in the past year, whereas several percent a year sero-conversions, that is, acquisition of infection, in that group was observed some years back.

There is a certain habitual discouragement about health education, which I am happy to say seems not to pertain. We have really got a terrifying product to sell, and it does work if we are willing to talk about it.

Senator WEICKER. Senator Pell?

Senator PELL. Thank you. I have just one question.

Dr. AuBuchon, what percentage of blood that is used in hospitals in America is contributed by the Red Cross, and what percentage if purchased commercially?

Dr. AuBuchon. About half of the blood that is used in this country is collected by the American Red Cross. The remaining portion is collected by community blood banks and hospitals. Almost all of the blood that is transfused in this country, 99 percent or greater, comes from volunteer donors. A very small portion, as I said, around one percent or less, comes from donors who are paid anything, paid money, for their donation.

The plasma derivatives industry does use paid donors. That is a different situation than what we are talking about here.

Senator Pell. Are the tests applied to the paid donors, too, or can they just walk off the street?

Dr. AuBuchon. The industries that produce plasma derivatives from paid donors are subject to FDA regulations, and they use all the same tests that we do.

Senator Pell. Thank you.

Senator Weicker. There is a vote in process. I will have to recess the Committee for a few minutes until I get back. I really wish the entire United States Senate would have an opportunity to hear you people, indeed, the entire Nation. I thank you very much for your very valuable testimony. If there are further questions, I would like to submit them to you for response for the record. I thank you very much.

The Committee will stand in recess.

[Short recess.]

Senator Weicker. The Committee will come to order.

The next panel is here at the request of Senator Hatch. We will begin with Dr. Vernon Mark, Associate Professor of Surgery at Harvard University. He will be followed by Anthony Robertson of the Research Testing and Development Corporation in Lexington, Georgia.

We are imminent of another vote, so I am going to get right down to the testimony. All the testimony in its entirety will be included in the record. I would suggest that you synopsize it.

Dr. Mark, it is a pleasure to have you here, and why don't you go ahead and proceed with your testimony?

## STATEMENTS OF DR. VERNON MARK, ASSOCIATE PROFESSOR OF SURGERY, HARVARD UNIVERSITY; AND ANTHONY ROBERTSON, RESEARCH TESTING AND DEVELOPMENT CORP., LEXINGTON, GA

Dr. Mark. Thank you very much, Senator, and I thank the Committee for allowing us to testify.

I have some very informal remarks, and first of all I would just like to say that I am an Associate Professor of Surgery at Harvard Medical School, that I am the retired Director of Neurosurgery at the Boston City Hospital, that I am on the staff of the Massachusetts General Hospital, and that I have been very actively involved for the last nine or ten years in the work of evaluating dementia. We have dementia clinics for the purpose of identifying the cause of the dementia and assessing possible treatments.

Unfortunately, HIV not only affects the immune system, but also affects the brain, and in many cases produces a very rapidly-advancing dementia.

I have just come from a national conference on HIV which was initiated by Dr. Robert Redfield, Colonel Burke of the United States Army, myself, other members of the staff from Harvard Medical School, from Duke University and the University of Miami.

This was a program put on for practicing physicians and surgeons, particularly surgeons, surgical specialists and general practitioners who are involved in invasive procedures. One of the things that we wanted to explore was the relationship of doctors to the practice of medicine in the era of AIDS when there is, for the first time in 50 years, an infectious disease which is potentially fatal which, although it is probably a very rare occurrence, can be contracted by physicians, and what our response should be and how we should respond to the challenge.

We were emphasizing one very special thing, and that is we recognize that there are conflicting agendas which all are very well-intentioned in terms of controlling this epidemic. But they have sort of a supernatant, other issues which tend to guide them. There is the conservative religious approach, which stresses moral values; the conservative approach, which is now suggesting that the AIDS epidemic is not as serious as we first thought, and therefore, we do not have to spend much money on this. There is the liberal point of view, which says that we have won our sexual freedoms with great difficulty over the last 30 years in the sexual revolution, and we do want to control AIDS, but not in a way which is going to infringe on sexual freedoms. And then there is the homosexual approach which says that we have been the principal victims of this disease and therefore we need to have homosexual civil rights, gay rights.

The question that we asked ourselves is, is there a purely medical agenda. And unfortunately, the answer that we got is that we really do not have a medical agenda right now, and one of the reasons we do not have this—I am not talking about the development of new drugs or the development of vaccines. I am suggesting that in the area of public policy we do not have a medical agenda because we do not have the facts to base such an agenda on.

In order to get those facts, we have to have some idea of how many people are infected in the United States and how rapidly this infection is advancing. And this can be done through cross-sectional, anonymous testing, that is, random anonymous testing. We have had the ability to do this since 1985, but we have not done it as yet. It even got to the point where it has been directed by the White House for the CDC to do this, and they now come back with the suggestion that they cannot do it, because they took a poll saying that 30 percent of people did not want to be tested. But to us, that meant that 70 percent, without any publicity, without any explanation, agreed to be tested. If they understand that this test is not infectious, that they are not going to be harmed by this, that it is completely anonymous, and that confidentiality will be strictly adhered to, and that we need this desperately, to understand what the compelling national interest is, to find out where our money should be spent to try to avoid having a public health catastrophe.

When we look at the statistics now available, which are mostly those people who have AIDS, you can compare us to an astronomer looking at a star. We are looking at something that happened ten years ago, not something that is happening now. It does not make any sense to have statistics that are ten years old, to look at the end stage of a disease and not be able to have some idea as to what is happening right now.

Now, there are two possible solutions to this problem in terms of controlling the spread of the disease. One of them, I am sure you must have heard already, and that is a widespread educational campaign involving the use of safer sex. And the other approach is a public health approach, which means identifying the individual who is infectious and counseling them so that the disease will not be spread to the people who are uninfected.

But it does not make any difference which approach you use; you still have to have population sample statistics. How would you know whether your educational campaign or whether your testing campaign is effective unless you do repeated probes to determine whether the disease is not only spreading into new demographic areas of society, but how rapidly it is spreading. The rate of spread is extremely important. And unfortunately, again, we do not have that data.

I would like to make one other comment. I do not want to take the Committee's time, and perhaps you could ask me questions afterwards, if you like. But I would like to make one other comment, which is the comment on confidentiality.

I am old enough so that I remember a time when medical confidentiality and doctors' confidentiality was present, that when a patient went to a doctor, the medical information was sacred, and no one else got that information. Now, to most people who have third-party insurance, Medicare, through the Health Care Finance Administration, Blue Cross/Blue Shield, Medicaid, or other private insurers, there is a proviso, at least in Massachusetts, that an individual in order to get that treatment agrees to have all the medical records reviewed by the insurer. And usually that information is used for utilization review as a matter of economy so that the insurance company, whether it is government or nongovernmental, can keep a close check as to whether the tests done are useful, whether they needed to be done, and so on, but in the meantime it allows that information to go into computer banks. And this is particularly true with any kind of workmen's compensation insurance, which can get right back to employers.

Now, whether this happens very often, I do not know. But the perception of the lack of confidentiality is there, and we need to do something; we need to have some kind of compromise so that we can still have utilization review, but not, perhaps, by the insurer and have good medical confidentiality. It is not only important in this, but it is important in other aspects of medicine coming along the line.

We are now getting new genetic test which might enable us to determine who is going to get diabetes or who is going to get Alzheimer's Disease or who is going to get cancer. Now, that kind of information simply should not be available to anyone except the individual concerned and his or her physician. It should not be available to the employer, it should not be available to the government. And we have to do something to be absolutely certain that this confidentiality is going to be as sacred as it once was.

Now, if we can get that data, and I think it is attainable if we work together on this, then I think that we can have contact tracing and reporting to State health departments—not Federal, but State health departments. State health departments and local health departments have a good record of confidentiality. They do not have the necessity of sharing their information with anyone, and they have accountability. Unfortunately, as far as confidentiality is concerned, even making laws about confidentiality are really not going to serve or solve the problem, because if someone has, for example, the HIV-positive or is positive for syphilis—and I have seen that in records that I have reviewed—and that area of the record is blacked out or whited out or yellowed out, it really does not take a medical genius, or anyone nearly even medically sophisticated, to figure out what the patient has and what has happened to them, just by looking at the other parts of the record.

So I would like to make a plea for that so that we can have a confidential aspect as far as the patient's diagnosis is concerned. And this is extremely important for physicians, because right now, physicians who are taking care of patients, and particularly surgeons, have to have a high level of vigilance. And if they assume that every patient that they operate on, that every patient that they do a procedure that requires the spilling of blood or the taking of blood, is infected with HIV, they will have to have very special kinds of precautions. And at first, they will have a high level of vigilance. But you know, doctors are just like anyone else. They get complacent, they get careless. And unless we are able to determine when we need that vigilance, there are going to be accidents, and I am concerned about the fact that it is possible that what is not a problem now, because there is probably a very low prevalence of this disease, may turn out to be a problem in the future when the prevalence of this disease increases.

I would leave my remarks, then, open to questions.

Senator **Weicker**. Dr. Mark, thank you very much for your very perceptive remarks. I think they will be of great assistance to the Committee, and I thank you. I might have a question. Let me see how we run on the votes down on the Senate Floor.

Our next witness is Anthony Robertson, of the Research, Testing and Development Corporation of Lexington, Georgia.

Mr. **Robertson**. Thank you very much, Senator, and I am very grateful to be here and appreciate it.

I shall be very brief, but I would like to remind the Committee of two or three things which I think are not given enough attention at the moment.

First of all, we should remember that only two years ago, we were really very optimistic. We felt that this was a disease that would not strike more than a few unfortunate people, and we felt that those who were infected with the virus had a very low risk of developing AIDS. And I think, although of course, we will not know the full answer until the end of the epidemic, I think most of us would agree, and certainly most medical people and scientists working on the disease would agree now that infection with the virus is very likely to be life-threatening, that at least 50 percent of those infected, and more likely 90 percent, will die within ten or twelve years.

This is a very rapid change. We were too optimistic to start with.

Two issues which I think are not addressed enough——

Senator **Weicker**. I have got to alert you, that was the bell for a vote, so if you could try to compact your testimony into five minutes, I would appreciate it.

Mr. **Robertson**. I shall do so.

One issue which is not addressed much is that of secondary infection. For the first time since good records have been kept, and certainly, for the first time since the Second World War, we are getting increased prevalences of tuberculosis and of syphilis. Interestingly, the syphilis is occurring not in people with AIDS so much, but in heterosexually active people. In people with AIDS, there is also an increased prevalence of syphilis which cannot be treated by the conventional chemotherapy.

This is true also of tuberculosis, which has spread to people not infected with the virus. And while in itself, that is not very dangerous, I think we must face the fact that we will get epidemics of diseases that have been under control.

There are many viral infections such as cytomegalo virus, which we will expect to see increasing in prevalence amongst those who are susceptible, such as pregnant women and young children, but who are not infected with the HIV virus. I think not enough attention has been given to the problem in the future of secondary infection.

The other aspect is numbers and data. We need raw data very badly. It is possible at the moment for rational people to argue about whether a quarter of a million or 2.5 million people are infected with the virus. This should not be the case. It would be very simple to get the statistics that we need to know what the current prevalence of the disease is and what the annual incidence is. Relatively small samples of 50,000 or 100,000 taken at relatively frequent intervals would allow us to know this.

Such testing can be quite anonymous; there are many ways of doing it, and I think it is extremely important to get these data so that we know the scope of the problem, so that we know where to put our resources, and so that we know how effective the actions that we are taking now have been and will be in the future.

Dr. Mark has reminded me that one of the issues with testing is that we must also have national standardization of the testing laboratories. It is possible to get very low false positive rates and very high specificity, as the Army experience has shown us. Clearly, with such a devastating disease, the accuracy of the test is vital.

Since it is possible to achieve a false positive rate of something like one in 100,000 or better, we must standardize testing laboratories throughout the country so that all achieve this level of testing.

Thank you.

Senator **Weicker**. Thank you very much, Mr. Robertson.

Just a couple of questions. First of all, given limited resources—and there are limited resources—I am not even satisfied that we are going to be able to meet the requirements of research and/or education in this year's budget—where do you feel the importance lies insofar as testing is concerned?

Now, the difficulty I have with many of the proposals that have come to the Senate Floor is, number one, obviously, the cost, but number two, invariably, the groups that are proposed to be tested are groups where there is low risk, and I really do not know what is to be derived of benefit from that kind of expenditure of funds. I would like you to address these two problems.

**Mr. ROBERTSON.** I think that is a very important issue. Of course, we do not really know the prevalence of the virus in any group, and we do not want to create a self-fulfilling prophecy for ourselves by not testing those——

**Senator WEICKER.** Well, I would suspect, for example—and I am only a layman—that persons going for a marriage license, probably that group—assuming the fact we are not going to be able to test everybody, and believe me when I say we are not; the money is not there to do it—I would assume that the benefit of that group being tested is going to be rather small. I would just guess that those who are going in for a marriage license probably have, for the most part, engaged in sexual practices which do not put them in the high risk category—that is not to say there are not those who obviously test positive. But it seems to me that given limited resources, again, we are not going ahead and placing the testing where it belongs. That is what bothers me.

Dr. Mark?

**Dr. MARK.** If I could respond to that, again, I would like to get back to population sample statistics, because there are tremendous variations in the statistics we have seen, even in marriage license applicants. In some cities in California, for example, they have had an unusual incidence; in others, practically none.

I think we not only have to look at demographic groups, we also have to look at geography. There are some areas of the country, particularly the megalopolis from Boston to Richmond and then down to Miami, in which there is a substantial problem, and also on the West Coast; there are peaks in various other parts of the country. There are large areas like the Northwest in which there is practically no prevalence right now, and to do testing there does not make any sense.

But the issue is really what is the compelling national interest. If we find, by doing population sample statistics, for example, that this disease is restricted to high-risk groups, there isn't any reason to do all of this testing then. But if we find that, by repeated testing, that it is going into various parts of the general population, then we have to put our resources where the tests indicate we should. But we cannot do it blindly; that is really our point in doing these sample statistics.

Furthermore, if in fact these tests show that there is a great danger, that some of these people who are looking at the figures are quite concerned about this, then it is going to come back to you gentlemen. If we have got a national emergency on our hands, just like the war, we are going to have to tighten our belts, pay more taxes, or do whatever we have to do to survive.

**Senator WEICKER.** So you do not doubt that we have a health emergency on our hands right now, do you?

**Dr. MARK.** We do. But the magnitude of it is the thing that we do not know.

**Mr. ROBERTSON.** Or, we do not know how rapidly it is growing.

Dr. MARK. No. That is another thing. I mean, we have estimates. We had biostatisticians from the Harvard School of Public Health, and we had epidemiologists from other parts of the country, and estimates varied as widely as between 400,000 being infected and over 2 million. Now, these are the top researchers in the country as far as statistics are concerned. Now, that is not because any of these people's models are bad. It is not because they are not doing good work. It is simply that models alone without data do not fulfill the requirements. It is a desperate situation that we need the sample statistics. It is not going to be that expensive in terms of all that we are talking about. And then we can appropriate money reasonably instead of without any knowledge.

I agree with you, though, that there is no sense in putting money into testing where the patients are not—but how can we find this out unless we do the sample statistics?

Senator WEICKER. Let me say this to you, Dr. Mark, and Mr. Robertson, that I do not disagree with the testimony that you are presenting. But I think if you were in my shoes on the Floor of the United States Senate, you would probably find that the testing argument is being used to substitute for concentrating on research and education. In other words, it is being thrown out there, not in the sense that you are throwing—you are throwing it out there as a man of medicine who needs these statistics—and I have no dispute with that; I am not going to say you are wrong at all, and I do not think you are wrong; I know you are not wrong—but to try to deflect interest away from these other two areas. That is what bothers me. It is not the fact that you do not deserve your statistics; you do, and they should be accurate. There is no question about that.

Mr. ROBERTSON. I think we both agree with you. It is wrong to deflect money from education, and it is wrong to deflect money from research, and there are limited resources.

I think also it is very important to remember that as for other viral diseases, we are probably not going to get a chemical cure, and we are almost certainly not going to get a vaccine. So the research, while important and vital, is not going to lead to quick solutions to the problem. The time course of the kind of research we are talking about is years, or perhaps decades, rather than a year or two. So we cannot wait. And that again re-emphasizes the value of rather cheap data. I mean, we know from the Army experience that testing, random sampling, is not expensive.

Dr. MARK. There is one very important public health speculation I would like to share with you, and that is that it might be possible with some of the newer drugs coming out, even with people who are infected, to cut down their infectiousness so that they are not a public health problem. It is the way the Army tried to deal finally, after their educational programs failed in World War II, with gonorrhea, by giving their troops prophylactic oral sulfathiazole. And it may be possible, now that we are getting a handle on viremia, on the actual amount of virus in the blood or semen—and we know that that is not constant; people are not continuously infectious, as we thought—it may be possible to find something which will, with checking, keep people's virus down so that they are not such a public health menace. And this may be another way, a more effective way, of stopping the spread of the disease.

Senator **WEICKER**. I want to thank both of you for your testimony. We have one more witness, and I want to be sure that witness has a chance to speak. But I want to thank you for contributing to the debate or discussion in a medical sense, in a scientific sense. None of us can be the losers for that, and I mean that; even though you present different points of view, I am delighted to hear them, and I think you have made a very positive contribution toward the deliberations of this Committee, and I want to thank you.

Dr. **MARK**. Thank you very much for having us.

Mr. **ROBERTSON**. Thank you, Senator.

Senator **WEICKER**. Thank you.

Our last witness is Dr. Gloria Rodriguez, AIDS Outreach Coordinator, of the New Jersey Department of Health.

Dr. Rodriguez, again, I am afraid I have got the constraints of this vote, which is going to end in about 15 minutes, so if you could please restrict yourself to about five to ten minutes, I would appreciate it. It is nice to have you here.

## STATEMENT OF DR. GLORIA RODRIGUEZ, AIDS OUTREACH COORDINATOR, DEPARTMENT OF HEALTH, NEWARK, NJ

Dr. **RODRIGUEZ**. I would like to thank the Committee for having one of the front-line workers, and I am able to speak on their behalf.

My name is Gloria Rodriguez. I am a public health consultant for the New Jersey State Department of Health, Division of Narcotics and Drug Abuse Control, the AIDS Program.

I have been in public health since 1975 as a medical social worker, working with minority and disadvantaged populations, including adolescents, adults and intravenous drug users. But since 1982, I have devoted my time to counseling and educating literally hundreds of individuals at risk for AIDS.

Acquired Immune Deficiency Syndrome is the number one public health problem in the Nation today, and as of November 1, over 42,000 Americans and over 2,700 New Jerseyans have been diagnosed with AIDS. Many more thousands are estimated as being infected with the human immunodeficiency virus.

In the absence of a vaccine or treatment, effective public information and educational efforts are our only means of combatting this deadly virus.

We are here supporting that any Federal funds appropriated for AIDS public health information and educational campaigns be allocated without any restrictions placed on them.

The key points I wish to make in support of this are the following.

We must not let our own values, attitudes and beliefs dictate sound public health practice. We must remember that AIDS is caused by a virus and not a lifestyle. The parameters of public health education and informational messages really should be left to the experts in the field.

We must not limit the scope of our educational messages by erecting additional barriers to the AIDS public health educational efforts. What I mean by "additional barriers" is that public health educators such as myself, when we try to do the education, and we try to give the educational messages, are confronted by already existing barriers such as community resistance, denial, low awareness from other groups regarding the issue of AIDS, distrust within our own communities, language and cultural differences, and in many cases illiteracy.

So, by imposing additional barriers and constraints on the messages that we give, we are really making this an impossible task to do.

Also, any limitations imposed on sound alternative prevention messages besides abstinence will severely impede the effective arrest of the virus.

For examples like that, when I am in the front line, and I have a client coming in to me for advice and counseling, if that client is an adult who is already engaged in sexual activity or drug-using behavior, "Just say no" is not going to suffice. And if I have information that will prevent this person from becoming infected or infecting other people, then as a public health official, I have a responsibility to provide that information to this individual.

Again, we must target the education and informational messages to specific populations, or else we will in effect be party to the propagation of this virus, which is clearly in contradiction to the mandates given to public health officials.

In closing, I would like to state that my goal in educating and counseling my clients has always been to make them aware of the potential choices that they have to provide varying levels of protection against the AIDS virus; to encourage them to seek the safest one, and to instill in them a sense of personal responsibility for their health and the health of others. A policy restricting these messages would be limited and short-sighted and would severely impact my ability and the ability of other public health educators to effectively contribute to halt the spread of this virus.

The public has a right to this information. They are putting their trust in us. If we fail them, many American lives will be lost unnecessarily, and ultimately, we will fail ourselves.

Thank you.

Senator **WEICKER**. Dr. Rodriguez, thank you very much.

It has been recently reported that I.V. drug users now constitute the majority of AIDS cases reported in New York City, and I imagine it probably would not vary too much in New Jersey; and indeed, a similar report was made in my own home State of Connecticut.

Dr. **RODRIGUEZ**. Right.

Senator **WEICKER**. What recommendations do you have for educating a population that seems to be continuing to spread the AIDS virus, and what can we do to prevent the further spread of the virus?

More particularly, I notice there have been proposals about issuing free needles, et cetera. I would just like to get your viewpoint on this aspect of the problem.

Dr. **RODRIGUEZ**. Basically, the policy of our State and public health policy, sound public health policy, would be to encourage individuals who are actively using drugs to stop and seek treatment.

Obviously, that would be the first message, loud and clear, that should be given.

In other States and other cities, we have some knowledge that informational messages stating for individuals to clean their needles or their sets; some data coming out of San Francisco indicate that addicts have been able to utilize this information to their advantage. It is sketchy.

We have some data from The Netherlands indicating that there might be some measure of results in providing free needles.

Obviously, we feel that to stop drug usage would be the best; to expand the drug treatment capabilities of States so addicts can come in to treatment would be the most adequate thing we can do for them.

The more addicts share and the more addicts use drugs, the least likely they are to engage in safer behavior by not sharing needles and by sterilizing them using bleach. Obviously, in the meantime—and this is what sometimes we tell addicts—in the meantime, until they get to treatment, these are the other alternative things they can do in order to prevent getting infected.

But ultimately, our goal is to get addicts to stop using drugs.

Senator **Weicker**. Thank you very, very much for your testimony. Thank you for taking the time to be with us.

Dr. **Rodriguez**. Thank you.

Senator **Weicker**. The Committee will stand in adjournment. Thank you very much.

[Whereupon, at 12:50 p.m., the Committee was adjourned.]

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